



All Ireland Institute of  
Hospice and Palliative Care



## **REPORT**

# **“A SYSTEMATIC REVIEW OF PALLIATIVE CARE RESEARCH ON THE ISLAND OF IRELAND”**

**Authors: Dr Sonja McIlfatrick<sup>i,ii</sup> and Dr Tara Murphy<sup>i</sup>**

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i. All Ireland Institute of Hospice and Palliative Care.

ii. Institute of Nursing Research, University of Ulster, Northern Ireland.

**Corresponding author:** Dr Sonja McIlfatrick, University of Ulster, Room 12 J11, Shore Road, Newtownabbey, Co. Antrim, Northern Ireland, BT37 OQB (email: [sj.mcilfatrick@ulster.ac.uk](mailto:sj.mcilfatrick@ulster.ac.uk) )

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## **1. Acknowledgements**

This work was supported by All Ireland Institute of Hospice and Palliative Care (AIHPC). AIHPC is an all-island organisation comprised of a Consortium of partner organisations, including health agencies and universities, all working to improve the experience of supportive, palliative and end-of-life care on the island of Ireland by enhancing the capacity to develop knowledge, promote learning, influence policy and shape practice.

## **2. Executive Summary**

As palliative care research continues to expand across Europe, and the world, questions about the nature and type of research undertaken and research priorities exist. This systematic review examined palliative care research conducted on the island of Ireland over the last decade. A comprehensive search strategy was implemented and strict eligibility criteria were applied in order to identify relevant peer-reviewed journal articles. Data sources: Criteria for selection included published peer-reviewed articles and reports of research undertaken in Ireland and Northern Ireland, published between January 2002 and May 2012. These were assessed in relation to year, setting, sample size, research methodology, and key outcomes. 412 publications were identified for screening and their abstracts obtained. After eliminating articles that did not meet the inclusion criteria, 151 remained for further analysis. A thematic analysis of 128 studies published between 2006 and 2012 revealed eight core themes: (1) specific groups/ populations; (2) services and settings; (3) management of symptoms (physical, psychological, social); (4) bereavement; (5) communication and education; (6) death and dying; (7) spirituality; and (8) complementary and alternative medicine/ intervention (CAM). There was an upward trend in the number of publications in palliative care research over the last ten years with over 72% of studies being published within the previous four years. A slightly higher number of studies were quantitative. Examining palliative care research undertaken is essential for developing priority areas for further research. There is a great need for future strategic direction and collaboration both nationally and internationally.

### 3. Introduction

Changing demographic trends including an ageing population, increased life expectancy for individuals living with life-limiting illnesses, and the impact of illness on individuals' physical, psychological and social wellbeing means that the demand for high quality palliative care services is expected to increase.<sup>1</sup> Estimates from Europe indicate that 3.2 million European citizens are newly diagnosed with cancer and that 1.7 million deaths occur annually.<sup>2</sup> The World Health Organisation (WHO) (2003) predicted that the number of people dying from cancer each year will increase to over 2.1 million by 2020 (a 24% increase).<sup>3</sup> This similar pattern can be noted nationally. For example, in the United Kingdom, a 17% increase in annual number of deaths is expected, along with an increase in the percentage of deaths of those aged 85 years or older, from 32% in 2003 to 44% in 2030.<sup>4</sup> Data from the World Cancer Research Fund International indicates that cancer cases in Ireland could increase by as much as 72% by 2030.<sup>5</sup> According to Ireland's Central Statistics Office<sup>6</sup>, the Irish population is gradually ageing with a predicted doubling of numbers for those aged 85 years by 2021.<sup>6</sup> This is predicted to coincide with an increase in disease prevalence between 2007 and 2021 for diseases including cancer as well as chronic conditions such as cardiovascular and respiratory diseases<sup>7</sup> Such data has great implications on palliative care service provision as estimates show that each year, 1.6 million cancer patients in Europe experience pain related to their disease, one third of them will require complex treatment and a significant number also experience distressing symptoms.<sup>8</sup> This picture is further complicated by ongoing economic challenges, resulting in cuts to services, staff numbers and resources. Such rising health care costs make it even more critical for services to demonstrate their effectiveness.<sup>9, 10</sup> Research that can inform evidence-based practice and demonstrate improved outcomes and cost effectiveness for a range of services and interventions in palliative care is therefore required.<sup>9-11</sup>

Palliative care is defined by World Health Organisation (WHO) as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems<sup>12</sup>. Many studies in palliative care report that the majority of people would prefer to die at home.<sup>13, 14</sup> Despite this, the evidence would suggest that people are more likely to die in an institutional setting an ongoing trend observed in a

number of different countries.<sup>13</sup> In a study of deaths in six European countries, Cohen et al<sup>15</sup> found that the proportion of cancer deaths occurring at home in 2003 ranged from 12.7 per cent in Norway, to 22-23 per cent in England and Wales, 27.9 per cent in Belgium, 35.8 per cent in Italy (2002 data) to 45.4 per cent in the Netherlands. In line with the international literature, available Irish survey data suggests that almost two thirds of older people in Ireland would prefer to be cared for at home if they were dying<sup>16</sup> and that the majority (48%) of deaths in the Republic of Ireland take place in acute hospitals.<sup>17</sup>

Within Europe it has been noted that variations in access to care, care quality, and research infrastructure persist. In the 2010 quality-of-death index that ranked countries according to their provision of end-of-life care, it was found that the United Kingdom ranked first and Ireland ranked fourth.<sup>18</sup> Whilst this is benefit questions exist around evidence in relation to the nature and type of research that is being undertaken. Higginson<sup>10</sup> argued that palliative care would benefit substantially from more outcome-based research being undertaken on its behalf, using a range of methods, for a diverse range of illnesses and populations. However Chalmers & Glasziou<sup>19</sup> raise concerns about the extent to which health-focused outcomes as prioritised by researchers would be considered priorities by patients, families or clinicians.

Undeniably, the consensus among international research experts, groups and lead organisations in palliative care is that there is a pressing need for clinically-relevant, collaborative, interdisciplinary, and strategic approaches to palliative care research.<sup>10, 20-25</sup> For example, the National Hospice and Palliative Care Organisation (NHPCO)<sup>24</sup> emphasised the need for collaborative research activities but equally recognised the challenges that can occur when the academic and clinical worlds collide. Both Higginson<sup>10</sup> and Kaasa<sup>26</sup> emphasised the need for collaborative research at all levels as well as considerations for research capacity-building.

It is evident that research in palliative and end-of-life care at all levels and in particular outcomes-focused and cost effectiveness research is needed in order to improve service delivery and ultimately, optimise patients' quality of life. With a growing ageing population, an increase in the prevalence of chronic diseases, and the consequences of both in terms of medical expenditure, it is anticipated that the need for palliative and end-of-life care will intensify resulting in a greater need for research in this area. Within the context of considering research priorities in palliative care, the current authors set out to explore the nature of palliative care research undertaken on the island of Ireland in order to examine its relevance and overall contribution to the area of palliative and end of life care.

## 4. Methodology

### Aims

The aim of the systematic review was to identify peer-reviewed journal articles that described palliative care research studies undertaken on the island of Ireland over the last decade. The specific objectives of the review were:

- a. To source the literature published between January 2002 and May 2012.
- b. To provide a thematic analysis of peer-reviewed journal articles published over the last five years.
- c. To examine study characteristics in terms of setting, sample, research methodology, and key outcomes.
- d. To contextualise palliative care research on the island of the Ireland internationally.

### Methods

#### *Search strategy*

The review was undertaken to identify research conducted in palliative care across the island of Ireland, within the last 10 years. The following standard bibliographic databases were searched (CINAHL, MEDLINE, SocINDEX, PsychInfo, PUBMED, Cochrane and ScienceDirect as well as the Irish Health Repository 'LENUS'). A combination of the following search terms were used with the Boolean phrase 'and/or' in order to maximise the type and range of material captured in the search: ("palliative" or "hospice" or "terminal" or "end-of-life"), ("palliative care" or "hospice care" or "terminal care" or "end-of-life care"), ("dying" or "death" or "terminal" or "terminally"), ("palliative" or "palliation" or "palliating" or "palliate" or "palliatively" or "palliat"), ("malignant" or "non-malignant"), ("pain" or "pain management" or "pain prevention" or "pain control"), ("symptom(s)" or "symptom management"), ("bereavement" or "bereaved" or "grief" or "grieving"), ("service design" or "service delivery" or "intervention"). Additional search terms 'Ireland', 'Northern Ireland' or 'Irish' were applied in order to increase the sensitivity of the search. Publications were selected based on the following inclusion criteria:

- a) Research output published between January 2002 and May 2012;
- b) Research conducted on the island of Ireland;
- c) Research relevant to palliative care.

A general review of key hospice and palliative care websites in Ireland and Northern Ireland was also conducted. In two cases, information managers/ librarians were contacted directly about research funded and/or published by their organisations within the last decade. Given the volume of documents initially generated, the search was solely limited to peer-reviewed journal articles thereby excluding other types of publications such as conference papers, newsletters, editorials, commentaries, discussion documents, and unpublished theses. Systematic reviews were included given their rigor and reliability. A separate analysis of commissioned reports on research outputs in palliative care was also carried out. The titles and abstracts of publications returned in the database results were manually reviewed in order to confirm their relevancy to palliative care; that they were research-focused; and were studies conducted on the island of Ireland.

#### *Data extraction*

All citations generated through the search were exported to Endnote®. Full text articles were retrieved where available in order to facilitate the review process. Citations were initially organised according to date (i.e. pre and post 2006) and reference type (i.e. journal article, conference paper, report, book, newsletter, editorial, etc). All journal articles were formally included in the review and their abstracts re-examined. Duplicates were removed where there was more than one article reporting on the same study. In this case the reviewers chose to select the earliest publication arising from these studies. An initial review of the articles separated them into seven broad thematic headings that best described the research focus: (1) understanding palliative care; (2) treatment and intervention; (3) training and education; (4) service delivery; (5) measurement and evaluation; (6) methodological and ethical issues; and (7) strategy and policy. The reviewers, together and separately, categorised the articles under one of these headings with a view to refining the headings further into the process. Where agreement was not reached, the reviewers examined the full text article where available and re-categorised.

A second review of the articles identified additional studies that were deemed not to meet the inclusion criteria. For example, studies drawing on Irish subsamples; reporting on staff feedback surveys as part of an education/ curriculum development initiative; outlining study protocols; as well as literature reviews. A list of the remaining studies was developed and data were gathered on setting and/or sample size, research methodology (design/ methods),

standardised instruments (where applicable), and key outcomes. The third and final review of articles involving re-examination of the original thematic headings identified eight core and more meaningful categories which are reported below.

## 5. Key Findings

A flow diagram detailing the selection of studies is detailed in Figure 1. The electronic literature searches identified 412 potential publications for screening after which duplicates were removed. The titles and abstracts of the remaining 388 publications were reviewed as well as publication type. This resulted in a total of 186 documents being excluded from the main review including books/ book sections, conference papers/ abstracts, newspaper articles/ bulletins, and discussions/ editorials/ commentaries/ journal articles (e.g. literature reviews; study protocols; discussions). Following this, 202 peer-review journal articles were identified for screening. A second review of abstracts for relevancy found that 51 articles did not meet the inclusion criteria. The final review identified eight core themes or headings which included 151 studies published over the period under examination.

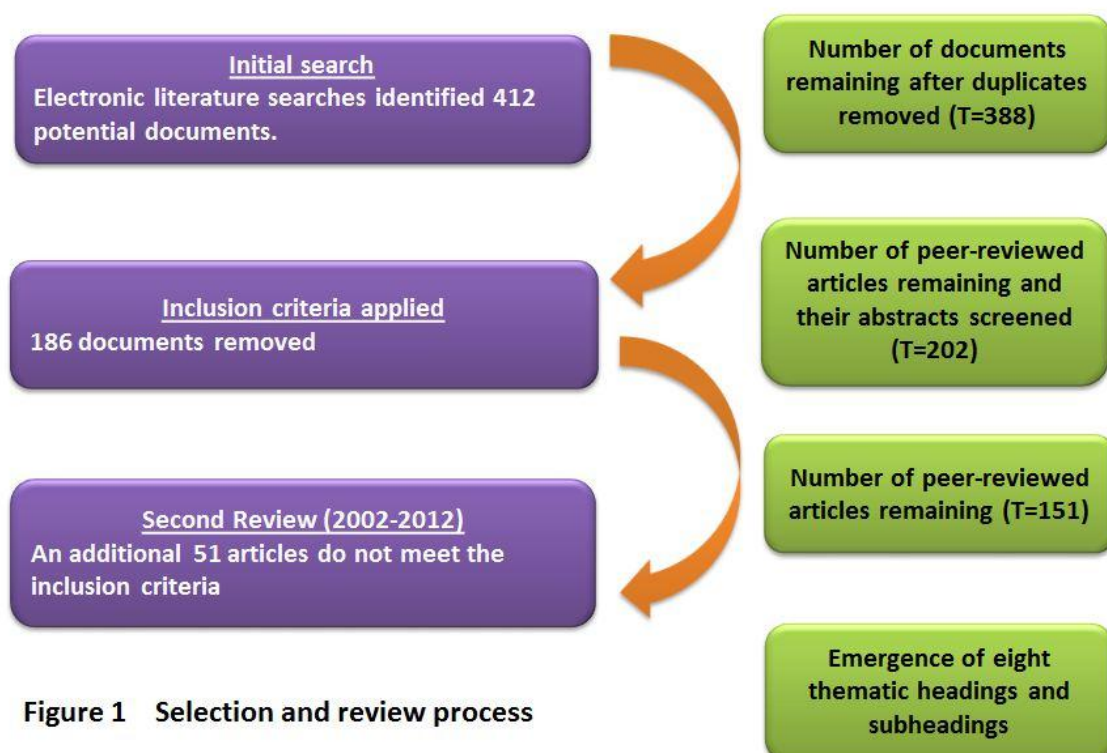
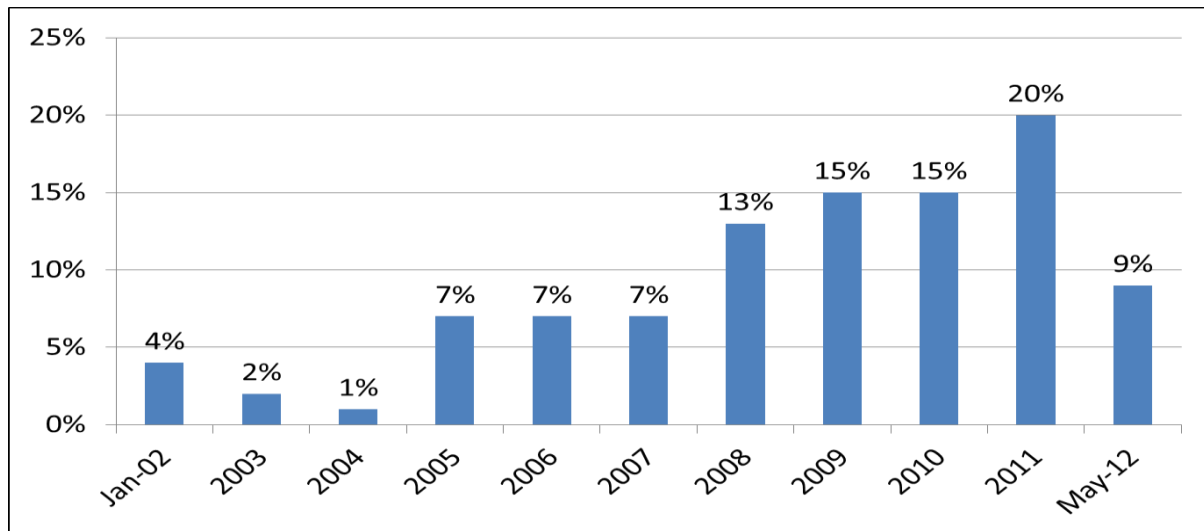


Figure 1 Selection and review process

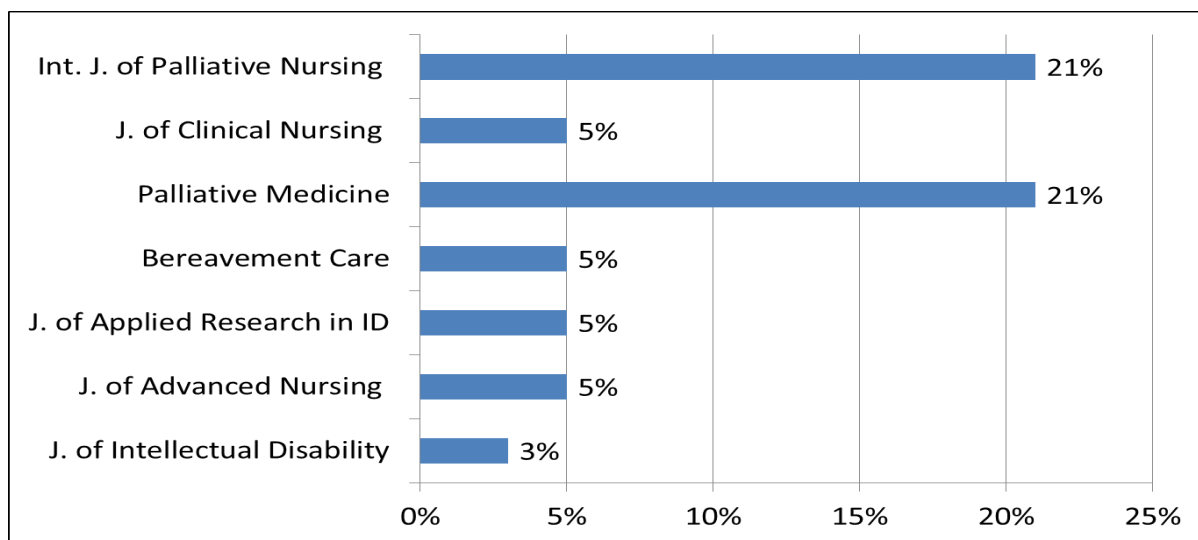


There was an upward trend in the number of studies in palliative care research published from January 2002 to May 2012 with over 72% being published within the previous four years (Figure 2).



**Figure 2. Percentage of peer-reviewed articles by year of publication.**

Papers were published in a total of 86 national and international journals the most popular being Palliative Medicine (21%) and the International Journal of Palliative Nursing (21%) (Figure 3). Interestingly, there were no known studies published on palliative care research in Palliative Medicine pre-2006. Other popular journals included the Journal of Advanced Nursing (5%), the Journal of Clinical Nursing (5%), and two journals in the area of intellectual disability research i.e. Journal of Applied Research in Intellectual Disability (5%) and Journal of Intellectual Disability Research (3%). For the purposes of the current review, the authors focused on studies published between January 2006 and May 2012. A table of references reviewed as part of the systematic review is included as Appendix 1.



**Figure 3. Top 7 most popular journals (2002-2012).**

In terms of research design, 41% of studies were descriptive quantitative in nature compared to 38% that were qualitative. Other study designs included mixed methods (12%), retrospective note reviews (5%), and systematic reviews (3%). Surveys and questionnaires (in some cases postal) were the primary quantitative research methods employed while the most frequently used qualitative methods were individual and focus group interviews. Twenty-five (20%) studies used a wide range of clinical and/or research-developed standardised measures with palliative care populations including carers and professionals (Table 1). There was wide variation in terms of sample size across the individual studies with the majority based on samples sizes of less than 100. Studies were undertaken in a range of settings including acute hospitals, the community/ home, generalist and specialist services (e.g. intellectual disability, cancer, and palliative care), hospices, and nursing homes.

Eight core themes emerged after re-examination of the remaining articles: (1) specific groups/ populations; (2) services and settings; (3) symptoms (physical, psychosocial); (4) bereavement; (5) communication and education; (6) death and dying; (7) spirituality; and (8) complementary and alternative medicine/ intervention (CAM) (Table 2).

**Table 1.** List of standardised instruments used in 25 studies.

| Core Theme                                | Standardised measurement tools   |
|---|--|
| Bereavement                               | <ul style="list-style-type: none"> <li>Texas Revised Inventory of Grief<sup>38</sup></li> <li>Santa Clara Strength of Religious Faith Questionnaire<sup>39</sup></li> </ul>  |
| Services and settings                     | <ul style="list-style-type: none"> <li>Use of Chronic Care Model Elements Survey<sup>40</sup></li> <li>Dependency tool<sup>41</sup></li> <li>Dependency tool<sup>42</sup></li> </ul>   |
| Specific groups (dementia)                | <ul style="list-style-type: none"> <li>Diagnostic and Statistical Manual of Mental Disorders-Revised IV (DSM-R IV) edition<sup>43</sup></li> <li>NINCDS-ADRDA criteria<sup>44</sup></li> <li>Mini Mental State Examination<sup>45</sup></li> <li>Eysenck personality questionnaire<sup>46</sup></li> <li>Zarit Burden Inventory<sup>47</sup></li> <li>Brief COPE Inventory<sup>48</sup></li> <li>Center for Epidemiological Studies Depression Scale -10<sup>49</sup></li> <li>Lubben social network scale<sup>50</sup></li> <li>Neuropsychiatric Inventory<sup>51</sup></li> <li>Disability Assessment for Dementia scale<sup>52</sup></li> <li>10-item self-efficacy scale<sup>53</sup></li> </ul>   |
| Specific groups (intellectual disability) | <ul style="list-style-type: none"> <li>Complicated Grief Questionnaire for People with ID (version of the Inventory of Complicated Grief<sup>54</sup></li> <li>Index of Social Competence<sup>55</sup></li> <li>Bereavement History Questionnaire (adapted)<sup>56</sup></li> </ul>  |
| Specific groups (malignant)               | <ul style="list-style-type: none"> <li>Eastern Cooperative Oncology Group Performance Status Rating (ECOG-PSR)<sup>57</sup></li> <li>EQ-5D<sup>58</sup></li> <li>Hospital and Anxiety Depression Scale (HADS)<sup>59</sup></li> <li>EORTC QLQ-C30 (version 3.0)<sup>60</sup></li> <li>Demoralization Scale<sup>61</sup></li> <li>Beck Depression Inventory (2nd edition)<sup>62</sup></li> <li>Beck Hopelessness Scale<sup>63</sup></li> <li>Schedule of Attitudes toward Hastened Death<sup>64</sup></li> <li>McGill Quality of Life Questionnaire<sup>65</sup></li> <li>Hunter's Opinions and Personal Expectations Scale<sup>66</sup></li> <li>Patient Health Questionnaire<sup>67</sup></li> </ul> |
| Specific groups (non-malignant)           | <ul style="list-style-type: none"> <li>Short Form 36 (SF-36)<sup>68</sup></li> <li>HADS Questionnaire<sup>59</sup></li> </ul>  |
| Symptom management (psychosocial)         | <ul style="list-style-type: none"> <li>HADS Questionnaire<sup>59</sup></li> </ul>  |
| Management of symptoms (pain)             | <ul style="list-style-type: none"> <li>Chronic Pain Grade Questionnaire<sup>69</sup></li> <li>Client Services Receipt Inventory<sup>70, 71</sup></li> <li>Level of Expressed Need Questionnaire<sup>72, 73</sup></li> <li>Pain Attitudes Questionnaire<sup>74</sup></li> <li>Pain Beliefs Questionnaire<sup>75</sup></li> </ul>  |
| Symptoms (delirium)                       | <ul style="list-style-type: none"> <li>Delirium Rating Scale- Revised-98 (DRS-R98)<sup>76</sup></li> <li>Cognitive Test for Delirium (CTD)<sup>77</sup></li> <li>Delirium Motor Subtype Scale (DMSS)<sup>78</sup></li> <li>Delirium Etiology Rating Checklist<sup>79</sup></li> <li>DSM-IV<sup>43,</sup></li> <li>HADS Questionnaire<sup>59</sup></li> <li>Confusion Assessment Method (CAM)<sup>80</sup></li> <li>Memorial Delirium Assessment Scale (MDAS)<sup>81</sup></li> <li>Mini-Mental State Exam (MMSE)<sup>45</sup></li> </ul>   |

**Table 2.** Core themes and subthemes (2006-2012).

| <b>Core themes (N=128)</b>         | <b>Subthemes (N=128)</b>   | <b>Examples</b>   |
|------------------------------------|--|---|
| 1. Specific groups (n=51)          |  |   |
|                                    | Children (n=11)  | staff experiences; bereavement; symptoms; needs; service delivery                   |
|                                    | Intellectual disability (n=10)   | bereavement; staff training; carers' perceptions & experiences; dementia            |
|                                    | Malignant disease (n=7)  | palliative management; QoL  |
|                                    | COPD (n=6)   | education programme; needs and experiences; carers                                  |
|                                    | Dementia (n=3)   | health economics; self-efficacy   |
|                                    | Heart failure (n=3)  | nutrition; needs and experiences  |
|                                    | Older people (n=3)   | staff needs; attitudes; service models  |
|                                    | Parkinson's disease (n=4)  | carers' experiences   |
|                                    | Non-malignant disease (n=2)  | needs; service barriers   |
|                                    | Same-sex couples (n=1)   | bereavement   |
|                                    | Travellers (n=1)   | experiences   |
| 2. Management of symptoms (n=27)   |  |   |
|                                    | Delirium (n=13)  | profiling; predictions; depression; assessment tools                                |
|                                    | Pain (n=7)   | chronic pain; attitudes & barriers to pain management; help-seeking behaviour; cost |
|                                    | Cachexia (n=2)   | cancer care; needs; nutrition   |
|                                    | Nutrition (n=2)  | survival; weight assessment   |
|                                    | Psychological (n=2)  | use of CBT techniques; stress   |
|                                    | Other physical (n=1)   | symptom reporting   |
| 3. Services & settings (n=27)      | QoL and acute hospitals care; multi-visit service; palliative care unit; roles and responsibilities; waiting times; medication |   |
| 4. Bereavement (n=10)              | Needs assessment; bereaved partners; workplace; support  |   |
| 5. Communication & education (n=4) | Information/ education needs; professional development; blogging   |   |
| 6. Death & dying (n=5)             | Public awareness; moment of death and experiences;   |   |
| 7. Spirituality (n=3)              | Staff experiences; chaplaincy service; religion  |   |
| 8. CAM (n=1)                       | Oncology   |   |

Research focusing on specific groups (40%, n=51) was the most popular theme followed by symptoms (21%, n=27), and services and setting (21%, n=27). Specific groups or subthemes such as children (11 studies), intellectual disability (10 studies), and malignant disease (7 studies) were most popularly researched populations while there were noticeably fewer studies on minority groups such as same sex couples (1 study), individuals from the Travelling Community (1 study), and those with other non-malignant illnesses (2 studies). A

common thread running underlining this theme was the exploration of the needs, experiences and perceptions of service users, carers and professionals in relation to illness and palliative care services. Similarly, there were several studies examining bereavement in relation to children and separately, intellectual disability populations. While the reviewers in this review identified 'bereavement' as a separate theme in itself, the latter had a more generic focus.

'Management of Symptoms', ranging from physical to psychosocial manifestations, was the focus of 27 studies. The most frequently researched areas were delirium (13 studies) and pain (7 studies), followed by cachexia (4 studies), nutrition (n=2) and psychological symptoms (n=2). Interestingly studies assigned to this theme were more likely to implement standardised instruments in the gathering of data than any other themes. Research into services and settings (21%, n=27 studies) addressed issues such as quality of life, roles and responsibilities of professionals, and delivering palliative care in general and specialist settings. Other notable themes of research included bereavement (8%, n=10 studies), death & dying (4%, n=5 studies), communication & education (3%, n=4 studies), and spirituality (2%, n=3 studies). Only one study included in the current review focused on CAM.

For the 28 commissioned reports briefly analysed, the majority of them fell under the core themes 'services and settings' (6 studies) and 'specific groups: children' (5 studies). Four reports explored perceptions and experiences of 'death and dying'. Further reports focused on 'specific groups: older people' (2 studies) and 'communication & education' (2 studies) as well as the areas of dementia, intellectual disability, cachexia, carers, and Alzheimer's disease.

## **Discussion**

The findings from this study clearly show that palliative care research is on the increase in Ireland, particularly over the last five years. This would be reflective of the international perspective. Various reasons have been suggested for this international increase in palliative care research, such as the recognition of palliative care and its contribution as evidenced by WHO<sup>12</sup>; investments in some well-funded palliative care research initiatives in Europe, Canada, the USA and Australia<sup>27-31</sup> and global developments in mapping levels of

palliative care development<sup>32</sup>. According to Sigurdardottir et al.<sup>25</sup> the state of palliative care research can be closely linked to the development of clinical palliative care services in a country or a region. They argued that there is a strong link between specialisation, training and research and that recruitment is a significant issue. Therefore establishing palliative medicine as a specialty as well as other relevant professional staff is essential for both improving capacity not only for clinical work but also for research. There is little doubt that such developments in Ireland, as evidenced within the Eurobarometer ratings for palliative care (Ireland ranked 5<sup>th</sup>)<sup>33</sup> and the Quality of Death Index (ranked 4<sup>th</sup>) have contributed to the increase in palliative care research undertaken in Ireland over the last five years. There are, however, questions as to whether the developments in palliative care research are in line with these ratings for palliative care provision.

The findings also clearly indicate a diverse range of research activity. This ranges from death and dying, symptom assessment, bereavement, communication to complementary and alternative approaches and a focus on different groups and populations. This diversity would be indicative of the different disciplines involved in palliative care research such as psychology, psychiatry, palliative medicine, nursing, general practice, social science and health services research, amongst many others. Whilst initially such diversity could be considered a weakness it can be equally considered as strength. For it is only through diversity, with a mixture of competences and perspectives, that complex research questions within the area of palliative care can be addressed both nationally and internationally.

### *Specific Groups and Settings*

The results indicated that major areas of research undertaken were focused on specific groups and populations as well as different settings. Such groups included children, people with intellectual disability as well as studies of non-malignant disease. This can be seen to address the need to go beyond cancer and undertake palliative care in relation to chronic diseases such as heart failure, coronary obstructive pulmonary disease (COPD), renal and liver diseases and dementia. Such a need was identified by Higginson<sup>10</sup> in an examination of palliative care services and international research agendas. This does reflect a changing paradigm for palliative care, where it is increasingly recognised that palliative care is appropriate and potentially beneficial at the time of diagnosis and for other conditions. Furthermore, this could be indicative of changes in demography. Interestingly, there were

fewer studies in settings involving primary care despite the growing preference for patients to be cared for at home.

### *Management of Symptoms*

A recent pan European survey of research in end of life cancer care, across 41 European countries (n=127 responses), found that the most frequently reported active research areas were pain, assessment and measurement tools, last days of life and quality of death<sup>25</sup>. This focus on symptomatology, (specifically pain, cachexia, fatigue, cognitive symptoms and delirium, breathlessness) was previously identified as one of the main areas for future research, in a workshop held by PRISMA (priorities for research and measurement in end of life care). This workshop involved 30 research experts in palliative care/medicine (85% from a medical background) representing 25 European countries<sup>25</sup>. According to Kaasa et al.<sup>34</sup> there is a need for research on the aetiology of symptoms, the development and testing of standardised instruments, and the development of evidence-based guidelines to inform clinical practice. This was in line with previous findings arising from a European Parliamentary report in which the need for palliative care research focused on the aetiology and management of symptoms and holistic approaches to palliative care were advocated.<sup>35</sup> Research focusing on symptom management was the second largest theme for palliative care research undertaken in Ireland with the two most researched areas being delirium and pain. It is noteworthy that this was focused in areas with key champions and leaders in the area. The continued research focus on symptom management is essential for palliative care practice with a clear need to undertake clinically relevant research, clearly aligning clinical and research agendas. Furthermore, there appears to be an absence of user/carer involvement in palliative care research in Ireland which is significant given the requirements for patient/public involvement by funders and those commissioning research.

### *Health services research*

The third key focus of published research undertaken in Ireland was focused around service provision and health settings. This focus on health services research that informs health care policy, planning and provision was also identified as a key area for future research in the PRISMA workshop<sup>9</sup>. It is interesting to note that a UK focused consultation for palliative care research demonstrated a greater emphasis on health economic aspects and service delivery<sup>36</sup>. A rationale for this may be the greater involvement of service funders and providers in the consultation. Regardless however, of the reasons behind this focus, the

importance of the health economic aspects of palliative care research cannot be underestimated. This is of great significance within the context of rising health care costs and the need for services to demonstrate their effectiveness<sup>9</sup>. Recent findings arising from an international Think Tank on global research priorities in health economics for palliative care identified four priority areas including (1) models and components of care and setting (e.g. rural vs. urban); (2) evaluation studies; (3) methodological considerations (e.g. analysing and interpreting economic data, development of agreed terminology); and (4) strategies for initiating studies and use of data.<sup>37</sup>

### *Methodological Rigour*

The findings from this study demonstrate some clear issues in terms of methodological rigour, a lack of measurement of clear outcomes and an over emphasis on needs based research. It was found that the studies were largely descriptive in design, (including both quantitative and qualitative research), with a wide variation in sample size and a lack of use of recognised standard measures and consideration of key outcomes. This indicates a paradox. Whilst it is acknowledged that research in palliative care is complex with difficulties in measuring multiple symptoms alongside ethical concerns, there is a need to focus on outcome based research. Such outcomes measures need to be patient centred, valid, reliable and applicable for both complex and more 'simple' intervention studies.<sup>26</sup> However, many outcomes measures such as quality of life or satisfaction are considered highly subjective and influenced by a range of variables including socioeconomic background, culture, gender, and so on.<sup>10</sup> Kaasa et al.<sup>22</sup> and later Kaasa et al.<sup>26</sup> highlighted the significant role that systematic reviews and randomised controlled trial (RCT) studies have in providing reliable scientific evidence and enabling researchers/clinicians to compare data and undertake meta-analyses. This appeared to be an area of deficit and one that requires further development for Ireland in terms of research capacity building. An increase in methodological rigour, with a focus on RCTs and systematic reviews is necessary in order to establish the evidence base for best practice.

### *Limitations*

One of the limitations of the systematic review is that the key words used to select publications may not have captured other studies in the area of palliative care which used different terminology. This may have excluded relevant peer-reviewed papers due to them not mentioning a keyword in their title, abstract or subject terms.



## **Conclusions**

This study provided baseline evidence of the nature and type of palliative care research undertaken within Ireland over the last decade. Some areas of significant strength were noted such as a clear focus to address the needs of specific groups and populations, focusing on palliative care beyond cancer. Furthermore, there was also evidence of research focusing on symptom management and palliative care service developments. Despite this, however, the research undertaken was clearly limited by issues relating to methodological rigour with a lack of measurement of outcomes, overemphasis on needs based research and limitations associated with sampling. Similar issues have been identified at a European and global level. Such an analysis is useful when seeking to identify areas for future research and research priorities. There is a clear need for future strategic direction and collaboration for palliative care research both nationally and internationally. Collaboration between palliative care researchers in the island of Ireland remains in its infancy. There is a need to maximise existing resources, leverage expertise and capability, and build critical mass in order to produce excellent, internationally-competitive research.

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# APPENDIX 1

# REVIEW OF PALLIATIVE CARE RESEARCH ON THE ISLAND OF IRELAND OVER THE LAST FIVE YEARS (2002-2012)

Jan 2002-Dec 2005

| Author, Year                           | Aim   | Sample/ Setting  | Research Design | Method | Outcome measures   | Key Findings of the Study   |
|--|---|--|-----------------|--------|--|---|
| <b>SPECIFIC GROUPS (NON-MALIGNANT)</b> |   |  |                 |        |  |   |
| <b>Cleary, J. et al (2005)</b>         | (a) To measure the overall quality of life of people receiving haemodialysis, (b) To compare the quality of life of the sample with that of the general population & (c) to identify any differences between the quality of life of people who are adequately dialysed and those inadequately dialysed. | Patients (n=97) undergoing haemodialysis treatment at a hospital | Quantitative    | Survey | 36-item Short Form Health Survey   | Patients receiving haemodialysis identified limitations in a number of areas including vitality, physical functioning and physical role limitations. They also reported significantly lower physical functioning when compared with general population norm-based scores. Differences were also found in mental health scores between patients who were well-dialysed and those less well-dialysed. |
| <b>SPECIFIC GROUPS (MALIGNANT)</b>     |   |  |                 |        |  |   |
| <b>Kealey, P. et al. (2005)</b>        | An evaluation of the domiciliary occupational therapy service provided for patients in the palliative stage of cancer care in North and West Belfast from the   | Patients (n=30) & carers (n=30)                                  | Quantitative    | Survey | Easi-Quest Patient and Staff Surveys, Reference Point Ltd), occupational therapy | High levels of satisfaction reported, however, there are gaps identified in service provision and a lack of clear information among patients and their carers about the role of the occupational therapist  |

|                                   | perspective of the patients and carers.   |  |   |                      | outcome measures | and the range of services they can provide.  |
|-----------------------------------|---|--|---|----------------------|------------------|--|
| <b>Kavanagh, E. et al. (2004)</b> | To describe case of a patient with a primary colonic adenocarcinoma who developed calcified pulmonary metastases while receiving palliative chemotherapy. | Patient (n=1)  | Retrospective clinical case note review | Documentary analysis | n/a              | Calcified pulmonary metastases are described in association with a variety of primary neoplasms.   |
| <b>O'Connor, A. et al. (2004)</b> | To report on the successful use of expandable metal stents in two cases of malignant gastric outlet obstruction.  | Two patients   | Qualitative                             | Case studies         | n/a              | The use of endoscopic stents as a primary palliative procedure has been well documented. Two cases are presented here, which highlight the benefits of this procedure in patients who develop recurrence at the site of a previous palliative gastroenterostomy. |
| <b>Curt, G. et al. (2003)</b>     | To assess cancer-related fatigue and compare to international findings  | 109 physicians & 160 nurses; cancer patients; hospital clinics | Quantitative                            | Survey               | n/a              | 53% of patients experiencing significant fatigue at least daily, and 80% at least monthly on both sides of the Atlantic. In other respects, such as duration of bouts of fatigue, how much and with whom patients discuss their fatigue                          |



symptoms, and economic impacts of fatigue, there are significant differences.

#### COMMUNICATION & EDUCATION APPROACHES

|                                  |   |  |                                  |                                 |     |   |
|----------------------------------|---|--|----------------------------------|---------------------------------|-----|---|
| <b>Dowling, S. et al. (2005)</b> | To ascertain what further training Irish GPs want in this discipline, and how such training might be delivered. | GPs (n=32)   | Mixed methods (Delphi technique) | Survey (incl. open-ended items) | n/a | GPs expressed the need for more training in the use of the syringe driver, newer treatments for pain and other symptoms, issues relating to polypharmacy, non-drug therapies, counselling and communication. Factors preventing GPs from availing themselves of further training include practice workload, difficulties in obtaining locum cover, distance and cost of courses, loss of personal time, and interference with family life. GPs would like further training to be multidisciplinary and practically orientated, and to include case discussions and workshops. |
| <b>Dowling, S. et al. (2005)</b> | To evaluate the training in palliative care received by GPs completing vocational training in Ireland.          | Final-year GP trainees (n=51) in Irish GP training schemes (n=10). | Quantitative                     | Survey                          | n/a | Teaching in the GP training schemes was formal and comprehensive. Over 40% admitted having no confidence in use of the syringe driver,  |

|                                   |  |                         |              |        |  |  |
|-----------------------------------|--|-------------------------|--------------|--------|--|--|
|                                   |  |                         |              |        |  | management of stoma problems, bereavement in children, and euthanasia; 57% indicated that further practical training in palliative care was of high priority for them. Trainees indicated that dealing with their own emotions was a significant source of stress.             |
| <b>Davidson, R. et al. (2005)</b> | To identify patient satisfaction with regard to various aspects of communication and perceived quality of care.                    | Cancer patients (n=339) | Quantitative | Survey | Patients' views of cancer services (NHS-developed) | Key findings are that there are a number of issues with regard to information and communication which can be clearly improved within Northern Ireland cancer services. The paper concludes that patient-professional communication should be tailored to meet individual need. |
| <b>Dowling, S. et al. (2003)</b>  | To establish the current status of undergraduate teaching in palliative care in this important discipline in Irish medical schools | Medical schools (n=5)   | Quantitative | Survey | n/a  | Identification of the relevant teachers proved to be difficult. In no school is the teaching centrally co-ordinated. All five medical schools have specific time dedicated to the teaching of palliative care; in two cases this is one day or less. All                       |

|  |   |                      |                                  |                                 |     |  |
|--|---|----------------------|----------------------------------|---------------------------------|-----|--|
|  |   |                      |                                  |                                 |     | schools covered most of the topics outlined in the curriculum. The majority of the teaching is by didactic lecture; there is some use of group discussion and case studies.  |
| <b>McIlfatrick, S.J. et al. (2003)</b> | To facilitate a strategic approach to cancer nursing research by identifying the research priorities of cancer nurses.  | Nurses (n=60)        | Mixed methods (Delphi technique) | Survey (incl. open-ended items) | n/a | The top priority areas identified were psychosocial issues, for example communication and information needs; professional issues relating to nurse burnout, stress and nurse-led care; and context of care issues including continuity of care.  |
| <b>Donaghy, K. et al. (2002)</b>       | To collect, analyse and summarize information on how team members perceive teamworking; compare team members' perceptions after a teambuilding workshop; and to evaluate the longer term effect of this training on the team. | Practitioners (n=67) | Mixed methods                    | Survey (incl. open-ended items) | n/a | A perception of understaffing was noted as being one of the largest negative influences on teamwork whereas the setting and maintaining of agreed team objectives and having sufficient education opportunity were positive influences. Although teambuilding sessions appear to have the potential to produce the desired benefits, |

they should not be initiated at a time when staff already feel anxiety over their workload.

|                                  |   |                          |              |               |     |  |
|----------------------------------|---|--------------------------|--------------|---------------|-----|--|
| <b>Timmins, F. et al. (2002)</b> | To examine reported stress in 12 areas commonly reported to cause stress to nursing students. | Nursing students (n=110) | Quantitative | Questionnaire | n/a | Stress exists for students in both the clinical and academic aspects of the programme. Financial constraints and academic-related concerns emerged as the most stressful areas for the students. A third of the students reported that relationships with teachers and staff on the ward cause some degree of stress. Five factors emerged as sources of stress. Firstly, 'academic' stress factors. The second and third components concern relationships, the former involving teaching-related staff, and the latter involving the clinical experience. |
|----------------------------------|---|--------------------------|--------------|---------------|-----|--|

#### SPECIFIC GROUPS (ID)

|                                |   |                                     |               |                                 |     |  |
|--------------------------------|---|-------------------------------------|---------------|---------------------------------|-----|--|
| <b>Dodd, P., et al. (2005)</b> | (a)To examine the type of experience people with intellectual disabilities have following bereavement, & (b) to | Service agencies; care staff (n=60) | Mixed methods | Survey (incl. open-ended items) | n/a | There appears to be cultural differences in the experience of bereavement for people with intellectual disabilities. This is important in the context of staff training and policy |
|--------------------------------|---|-------------------------------------|---------------|---------------------------------|-----|--|

|                                  | assess levels of staff training and support as perceived by senior managers.  |  |              |               |   | development in grief and bereavement.   |
|----------------------------------|---|--|--------------|---------------|---|---|
| <b>McEvoy, J. et al. (2005)</b>  | To explore relatives' perceptions of the grieving-process, concept of death and reactions to bereavement for their intellectually disabled family member. | Relatives (n=38)                                       | Quantitative | Questionnaire | n/a   | Many respondents reported post-bereavement reactions of adults with intellectual disabilities typical of the general population. Although the majority of respondents perceived their relative as not understanding the concept of death they were supportive of death education, did not view lack of knowledge as a barrier to grieving and were optimistic about supporting their relative following bereavement. Respondents with behaviourally challenging family members were less agreeable to death education and less optimistic about their ability to support. |
| <b>MacHale, R. et al. (2002)</b> | To investigate the impact of bereavement on people with learning disability.  | Adults (n=20) with learning disabilities & control gp. | Quantitative | Survey        | Psychiatric Assessment Schedule for Adults with a Developmental | With regard to psychiatric disturbance, significant differences were found for 'neurotic disorder' and for 'organic condition' among the  |

|  |   |                 |             |                        |   |  |
|--|---|-----------------|-------------|------------------------|---|--|
|  |   |                 |             |                        | Disability (PAS-ADD); Aberrant Behavior Checklist (ABC) | bereaved group on the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD). No difference was found for 'psychotic disorder' on the PAS-ADD. As regards challenging behaviour, significant differences were found for 'irritability', 'lethargy' and 'hyperactivity' among the bereaved group on the Aberrant Behavior Checklist (ABC). No differences were found for 'stereotypy' or 'inappropriate speech' on the ABC. |
| <b>COMPLEMENTARY &amp; ALTERNATIVE MEDICINE/INTERVENTION</b> |   |                 |             |                        |   |  |
| <b>Dunwoody, L. et al. (2002)</b>                            | To explore patients' experiences of aromatherapy using of a focus group interview | Cancer patients | Qualitative | Focus group interviews | n/a   | Eight themes emerged from the analysis, six of which have been acknowledged to some extent by previous authors: de-stressing effects of aromatherapy, the counselling role of the aromatherapist, aromatherapy as a reward, patient empowerment, communication through touch, and negative aspects of the  |

|                                    |  |  |   |                      |     |   |
|------------------------------------|--|--|---|----------------------|-----|---|
|                                    |  |  |   |                      |     | service. Two apparently new themes emerged concerned with security of context (where the aromatherapy took place) and preconceived perceptions of the value of aromatherapy as a treatment of cancer patients.  |
| <b>Wright, S. et al. (2002)</b>    | To explore clients' perceptions of the benefits of reflexology interventions on their QoL.           | Clients who received intervention (n=47) | Retrospective clinical case note review | Documentary analysis | n/a | Reflexology interventions were perceived to impact positively upon clients' levels of impairment and functional status, including physical and psychological function, with implications for general health perceptions.  |
| <b>BEREAVEMENT</b>                 |  |  |   |                      |     |   |
| <b>Gallagher, M. et al. (2005)</b> | To evaluate bereavement counselling provided by a voluntary charity from the perspective of clients. | Counsellors (n= 89)                      | Quantitative                            | Survey               | n/a | Paraprofessional voluntary counsellors can provide a counselling service to bereaved people that satisfies the majority of clients who report positive experiences in counselling and post-counselling outcomes, and generally rate their counselling as helpful. |

| SERVICE DELIVERY                   |  |  |              |               |     |   |
|------------------------------------|--|--|--------------|---------------|-----|---|
| <b>Ling, J. (2005)</b>             | To assess the current level of input from community-based clinical nurse specialists in palliative care into nursing homes in the Republic of Ireland. | community-based clinical nurse specialists in palliative care (n=63) | Quantitative | Survey        | n/a | All respondents had undertaken work with nursing homes. The main focus of interactions with nursing homes was on pain and symptom management and this was often provided by telephone. The majority of nurses were involved exclusively in care of patients with cancer, although 40% of respondents cared for patients with non-malignant diseases.  |
| <b>McDonnell, M. et al. (2002)</b> | To investigate registered nurses' perceptions of palliative care in district general hospitals.  | Nurses (n=263)   | Quantitative | Questionnaire | n/a | 70% of general ward nurses believe that managing care of the dying is an integral part of hospital care. However, their dissatisfaction with the care they give is reflected in the mere 8% who consider hospital an ideal setting for patients who are dying. A minority feel confident in discussing death and dying with the patient. Barriers to optimal palliative care on general wards were perceived as lack of appropriate |



|                                     |   |   |              |               |      |   |
|-------------------------------------|---|---|--------------|---------------|------|---|
|                                     |   |   |              |               |      | education and training, work pressures, and lack of support from medical colleagues and managers.   |
| <b>Sullivan, K.A. et al. (2005)</b> | To ascertain nurses' experience of working alongside an HAH (Hospice At Home) service.  | District nurses (n=162)                 | Quantitative | Questionnaire | n/a  | The findings support the idea that an HAH service can enable patients with advanced progressive disease to be cared for at home. While the findings of this study cannot be generalized, they add to the growing body of research about HAH services in palliative care.                              |
| <b>DEATH &amp; DYING</b>            |   |   |              |               |      |   |
| <b>Tiernan, E. et al. (2002)</b>    | To examine the relations between depressive symptoms and desire for early death (natural or by euthanasia or physician-assisted suicide) in terminally ill patients with cancer being cared for by a specialist palliative care team. | 142 terminally ill patients with cancer | Quantitative | Questionnaire | HADS | Only 2 patients expressed a strong wish for death by some form of suicide or euthanasia. 120 denied that they ever wished for early release. The desire for early death correlated with depression scores. Depressive symptoms were common in the whole group but few were on antidepressant therapy. |

|                                  |  |   |               |        |     |  |
|----------------------------------|--|---|---------------|--------|-----|--|
| <b>Tiernan, E. et al. (2002)</b> | To explore patients' preferences for place of death. | Patients (n=191) referred to a Hospice Home Care Team | Mixed methods | Survey | n/a | Over 80% expressed a preference to die at home. Almost 50% of those who expressed a preference for a home death actually died there. Of those admitted to hospital or hospice to die, uncontrolled symptoms and inability of family to cope were the main reasons precipitating admission. On closer assessment, it was felt that a significant minority of those admitted could have been cared for at home had additional resources been available in the community. |
|----------------------------------|--|---|---------------|--------|-----|--|

Jan 2006- May 2012

| Author, Year                        | Aim   | Sample/ Setting     | Research Design | Method        | Outcome measures   | Key Findings of the Study   |
|-------------------------------------|---|---------------------|-----------------|---------------|--|---|
| <b>THEME: BEREAVEMENT</b>           |   |                     |                 |               |  |   |
| <b>McGuinness, B. et al. (2011)</b> | To evaluate an innovative bereavement support group established in a hospice setting  | Participants (n=5)  | Quantitative    | Questionnaire | Texas Revised Inventory of Grief (TRIG); Adult Attitude to Grief (AAG) scale | This article explores some of the issues and dilemmas raised by evaluation in this context and discusses the importance of evaluation to developing a sound evidence base for innovative bereavement support work.  |
| Tracey, A. (2011)                   | To explore the experiences of women in Ireland who were bereaved of their mother in early life, and the lifelong impact of this loss. | Participants (n=26) | Qualitative     | Interviews    | n/a  | The death of participants' mothers had a profound impact throughout these women's childhoods and adult lives. They described the silence surrounding the death, their hunger for information about their mother, their coping strategies, their yearning for a mother figure, particularly in adolescence and when they married and gave birth themselves, and the effects on their own parenting |

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|                                  |   |                              |                   |               |   | capacity. A strong theme was their wish to speak publicly about their experiences.  |
| <b>Roberts, A. et al. (2010)</b> | To evaluate a bereavement information evening (BIE) as part of an adult bereavement support service   | Hospice (n=78 service users) | Quantitative      | Questionnaire | Texas Revised Inventory of Grief (TRIG) | BIE may provide mid-level support for people who need more than an information leaflet but not require more intensive one-to-one support. BIE may also provide access to more intensive bereavement services if necessary.  |
| <b>Agnew, A. et al. (2010)</b>   | To identify and review bereavement measurement tools to determine their suitability for use within bereavement services and hospice settings. |                              | Systematic Review | n/a           | n/a                                     | From 59 full-text papers appraised, 10 measurement tools were analysed in detail. Some tools had been tested on specific populations which limited transferability to specialist palliative care settings; some lacked adequate theoretical links and were not effective in discriminating between normal and complicated grief reactions; and some lacked clear evidence of validity or reliability. |

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| <b>Mc Guinness, B. (2009)</b>  | To explore Irish organisations' policies and procedures for supporting bereaved employees.  | Private, public & local government organisations (n=34) | Quantitative | Questionnaire         | n/a | While all the organisations had experienced employee-related bereavement within the previous 12 months, only four organisations had any written policy. The provision of compassionate leave varied widely and was often left to the discretion of line managers. |
| <b>Agnew, A. (2009)</b>        | To gain a deeper understanding of service user experiences of an adult bereavement group in a hospice setting in Northern Ireland | Service users (n=7)                                     | Qualitative  | Individual interviews | n/a | Two main themes emerged from the data: (1) how service users felt through their experience of attending the bereavement group meetings; and (2) the language and presentation required for an appropriate bereavement group information leaflet.                  |
| <b>Agnew, A. et al. (2008)</b> | To explore the experiences of partners bereaved through cancer.   | Bereaved partners (n=10)                                | Qualitative  | Individual interviews | n/a | Four themes emerged: cancer journey; impact of bereavement; process of adjustment and change; and experience of support services. Findings highlight key skills, knowledge and values that should be adopted by healthcare professionals                          |

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|  |   |  |               |  |   | involved in the provision of care to patients and families. Informal support networks were found to be the most valued source of help.  |
| <b>Roberts, A. et al. (2008)</b>                       | To evaluate a hospice-based bereavement support service.  | Hospice (n=243 service users)  | Quantitative  | Questionnaire                                      | Texas Revised Inventory of Grief; Santa Clara Strength of Religious Faith | Majority of service users were satisfied with the bereavement support service offered by the hospice. Some barriers to service delivery were also identified.   |
| <b>Walsh, T. et al. (2008)</b>                         | To examine a hospital-based bereavement   | Acute hospital (n=339 bereaved next-of-kin)                            | Mixed methods | Case review; questionnaire; focus group interviews | n/a   | Service is being used appropriately in that the outreach contact and information provision is welcomed. High proportions of those who described the death as sudden / unexpected made contact with the service further. |
| <b>THEME: COMMUNICATION APPROACHES &amp; EDUCATION</b> |   |  |               |  |   |   |
| <b>Lowney, A.C. et al. (2011)</b>                      | To examine the use of blogging by a patient receiving palliative care as a form of communication. | Specialist palliative care services; patient with pontine glioblastoma | Qualitative   | Case study   | n/a   | This case is noteworthy for a variety of reasons. It brought hospice staff into unfamiliar territory. It challenged them to see social media as a method  |

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| multiforme                           |  |   |              |               |     | of communication in life-limiting illness. It provided a rare insight into the patient's perception of hospice care. it allowed relative anonymity. It provided a fascinating account of each stage of illness. It offered a lasting legacy for the patient's family & friends. The blog also received media attention.                          |
| <b>Callinan, J. et al. (2010)</b>    | To understand the information needs of staff with regard to a new library and information service. To identify current access to and levels of skills in information literacy and ICT. To ascertain the need for training in those skills. | Hospice (n=48 staff including nurses, doctors/consultants, HR, volunteers, other health care professionals) | Quantitative | Questionnaire | n/a | Assistance with obtaining journal articles was rated most highly by respondents as being an important service. 83% indicated that they did not have access to online health databases. Small group classes were considered the preferred method of providing training. Afternoons were also considered more convenient for visiting the library. |
| <b>McIlfatrick, S. et al. (2010)</b> | To explore the educational needs of palliative link nurses.  | N=80  | Quantitative | Questionnaire | n/a | Education for palliative care link nurses needs to incorporate strategies to develop competence and confidence in practice   |

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|   |  |   |              |            |     | (knowing how) alongside skill-based learning (knowing that).  |
| <b>Johnston, G. (2007)</b>  | To evaluate a one year training scheme for Macmillan Nurses.   | Trainees (n=8), Practice-Based Facilitator (n= 7), other staff (n=6)  | Qualitative  | Interviews | n/a | Mainly positive. Trainees were perceived to be adequately prepared to adopt the role of a CNS on completion of the scheme. Some participants thought that more theory on symptom control and communication skills and a placement in a specialist palliative care centre should also be included.   |
| <b>THEME: COMPLEMENTARY &amp; ALTERNATIVE MEDICINE/INTERVENTION</b> |  |   |              |            |     |   |
| <b>Chang, K.H. et al. (2011)</b>                                    | To investigate the prevalence and predictors of Complementary and Alternative Medicine (CAM) use among cancer patients and non-cancer volunteers, and to assess the knowledge of and attitudes toward CAM use in oncology among health care professionals. | Outpatient and inpatient settings; cancer patients (n=219) and non-cancer volunteers (n=301); health care professionals (n=156) | Quantitative | Survey     | n/a | The overall prevalence of CAM use was 32.5%. Female gender, younger age, higher educational background, higher annual household income, private health insurance and non-Christian were factors associated with more likely CAM use. Most health care professionals thought they did not have adequate knowledge nor were up to date with the best evidence on CAM use in |



oncology. Health care professionals who used CAM were more likely to recommend it to patients.

#### THEME: DEATH & DYING

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| <b>Ryan, K. et al. (2011)</b>     | To explore how staff managed communication about death and dying with people with ID.                               | Community group homes, psychiatric hospitals, residential/ activity/sheltered work centres, general hospital & hospices; health care professionals, management & household staff (n=91) | Qualitative  | Focus group interviews (n=15) | n/a | Despite the general societal move toward conditional open awareness, participants in this study rarely discussed death and dying with people with ID who had life-limiting illnesses. Participants were strongly motivated to provide quality care and were willing to consider alternative approaches to communication if this would benefit people with ID. |
| <b>McCarthy, J. et al. (2010)</b> | To determine the public's understanding of and views about a range of ethical issues in relation to death and dying | 667 adult individuals   | Quantitative | Phone survey                  | n/a | The general public are unfamiliar with terms associated with end-of-life care. Although most want to be informed if they have a terminal illness, they also value family support in this regard. Most of the respondents believe that   |

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|                                      |   |   |             |                       |     | competent patients have the right to refuse life-saving treatment. Most Irish people are more concerned about the quality of their dying than death itself. Religious commitment is important to most Irish people.   |
| <b>Donnelly , S.M. et al. (2010)</b> | To explore relatives' experience of the moment of death in a tertiary referral hospital.                                | Relatives (n=24)  | Qualitative | Individual interviews | n/a | Four themes emerged: hospital as a place to die; quality of communication; location within hospital; and attributes of staff.   |
| <b>Donnelly, S.M. et al. (2009)</b>  | To examine the moment of death in a SPCU and in maximizing recall by interviewing relatives early in their bereavement. | Specialist palliative care unit; relatives (n=29) 20 families | Qualitative | Individual interviews | n/a | Participants provided a rich and detailed description of the moment of death often with humour. Additional themes were the importance of vigil; qualities of the staff; value of ritual and prayer and the environment of the SPCU. We cannot hear the stories of the dead. We can try to hear the stories of those who have witnessed dying. |

| THEME: SERVICES & SETTINGS      |   |   |   |             |  |  |
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| <b>Darker, C. et al. (2012)</b> | To provide baseline data on chronic disease management (CDM) provision in Irish general practice (GP).          | GPs (n=360)                               | Quantitative                            | Survey      | Use of Chronic Care Model Elements Survey; A Survey of Primary Care Physicians | The majority of GPs reported significant changes are needed in the Irish health care system to make CDM work better. Small numbers of routine clinical audits are being performed. Irish GPs use evidence based guidelines for treatment of diabetes, asthma / COPD and hypertension, to the same extent as international counterparts. Barriers to delivering chronic care include increased workload, lack of appropriate funding, with GPs interested in targeted payments. |
| <b>Afzal, N. et al. (2011)</b>  | To examine the quality of end-of-life care received by patients with & without dementia on acute medical wards. | Acute medical wards; patient notes (n=75) | Retrospective clinical case note review | Case review | n/a  | Dementia patients were significantly less likely to be referred to palliative care interventions, to be prescribed palliative drugs & to have carers involved in decision making.  |

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| <b>Agnew, A. et al. (2011)</b>    | To measure the satisfaction of District Nurses (DN) & service users with a multi-visit (MV) service.                                | District Nurses (n=21), service users (n=22)        | Quantitative                       | Phone survey   | n/a   | All the DN and service users reported that the MV service enabled patients to continue to be cared for in their own homes.   |
| <b>Blaney, J.M. et al. (2011)</b> | To establish factors that influence and contribute to the death of patients with cancer in acute hospitals in Northern Ireland      | 16 acute hospitals; 695 adults patients with cancer | Retrospective clinical note review | Case review  | n/a   | 3 main reasons for acute hospital deaths were uncovered. (1) 26% of patients were diagnosed with cancer during their last hospital admission. (2) Patients were very ill with nearly 79% admitted as an emergency, requiring medical attention as a result of cancer-related and urgent physical symptoms. (3) Despite 38% of patients specifically requesting discharge to their usual residence, hospice or other hospital, this was not achieved for various reasons. |
| <b>Bracken, M. et al. (2011)</b>  | To assess the utility of three needs assessment/dependency tools for use with patients in community-based palliative care services. | CNSs (n=22)   | Mixed methods                      | Assessments; individual and focus group interviews (n=2) | Vale prioritization tool; Graves & Payne (2007) and Birch et al. (1997) | The Vale prioritization tool appeared to be the most useful for prioritizing patient need and managing workload. Three themes emerged from the interviews: difficulties with   |

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|                                    |   |  |              |               | dependency tools | routine administration, points of divergence between the two dependency tools, and workload concerns. Findings raise questions about the overall utility and practical application of these kinds of tools with community-based palliative care patients.   |
| <b>Casey et al. (2011)</b>         | To explore the factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland | Acute and long-stay care settings; staff (n=33)            | Qualitative  | Interviews    | n/a              | Factors that influence provision of end-of-life care in Ireland were identified. The core category was 'dying well'. The potential to 'die well' was influenced by three factors, namely philosophy, culture and organisation of care, knowing the person and physical environment and resources. This study identified the factors that influence the provision of good end-of-life care for older people. |
| <b>McCormack, R. et al. (2011)</b> | To establish the reasons for phlebotomy and evaluate the usefulness of blood testing in the palliative setting.                               | Inpatients (n=65) with malignant & non-malignant diagnosis | Quantitative | Questionnaire | n/a              | The top three diagnosis were malignancy of bowel, ovary, and prostate respectively. The top three reasons for venepuncture were to manage   |

medications, establish the need for blood transfusion, and guide management of sepsis. 30% of phlebotomy sessions changed management, 40.7% ruled in an important diagnosis, and 86% ruled out an important diagnosis. 48% of phlebotomy sessions had at least one type of tests “added on” that in hindsight was unnecessary.

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| <b>Ó Céilleachair, A. (2011)</b> | To investigate time trends in place of death for colorectal cancer. | 10,175 colorectal cancer deaths | Quantitative | Database | n/a | Nearly half (49%) of deaths occurred in acute hospitals, 29% at home, 13% in hospices and 7% in nursing homes. Hospital deaths were unchanged over time. Hospice deaths rose from 6% in 1994 to 17% in 2003. Home deaths decreased significantly, but only in health boards with hospices. Nursing home deaths rose significantly in areas without hospices. |
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| <b>Devlin, M. et al. (2010)</b> | To explore the role of home-care workers in palliative and end of life care in the community.   | Community nurses (questionnaire, n=69; focus group, n=6)       | Mixed methods     | Questionnaire; focus group | n/a | Participants identified the need for additional support in the provision of end-of-life care, specifically during out-of-hours. Various restricting factors such as training deficits, need for support and supervision and communication issues were also identified.   |
| <b>McLean, S. et al. (2010)</b> | To report findings of a systematic review of current practice and attitudes towards the use of primary thromboprophylaxis for patients with advanced cancer in the palliative care setting. | Acute, outpatient and inpatient SPC settings; patients (n=198) | Systematic review | Studies examined (n=8)     | n/a | Patients find LMWH (low-molecular-weight-heparin) acceptable, particularly patients who experienced a sudden decline in performance status. Reluctance to prescribe LMWH is based on physicians' concerns regarding negative impact on quality of life, and lack of evidence specific to the palliative care setting. LMWH prophylaxis should be implemented in patients with a previously good performance status who have a transiently increased of VTE and no contraindications. |

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| <b>Sharp, L. et al. (2010)</b> | To investigate (time) trends in where cancer patients die to inform decisions about how healthcare should be organised to support those in need of end-of-life care. | 18,078 death certificates  | Quantitative  | Database?                   | n/a | 53% of deaths occurred in an acute hospital, 29% at home, 12% in hospices and 4% in nursing homes. Hospice deaths rose from 7% in 1994 to 15% in 2003, falling slightly in 2004-05. Hospital deaths were unchanged over time, but were more common in areas without hospices. Home deaths decreased significantly. Nursing home deaths rose significantly. These trends were not explained by temporal changes in the age-sex distribution of deaths. |
| <b>Curry, C. et al. (2009)</b> | To explore and address the palliative care education needs of staff working in two nursing homes.  | Registered nurses (n=4) and care assistants (n=8) in two nursing homes | Mixed methods | Questionnaire; focus groups | n/a | Providing palliative care education using a practice development framework enables and empowers staff to provide greatly improved end of life care to residents. 'Knowing the person' is an important aspect of caring for residents in nursing homes and life story work can be used to enhance their care.  |



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| <b>Roche-Fahy, V. et al. (2009)</b> | To explore the lived experience of nurses who provide comfort to palliative care patients in an acute setting in a small urban hospital.                                 | Acute hospital; general non-specialised nurses (n=12)   | Qualitative (Gadamerian hermeneutic phenomenology) | Individual interviews | n/a | Four main themes emerged as central to nurses' experiences: time needed to provide comfort; emotional labour of providing comfort; holistic approach involved in providing comfort; and education and expertise and their role in providing comfort.   |
| <b>Devlin, B. et al. (2008)</b>     | To evaluate a domiciliary blood transfusion home service for palliative care patients.   | Patients (n=11) who had received a domiciliary blood transfusion and who were in the palliative stage of their illness. | Quantitative                                       | Phone survey          | n/a | Domiciliary blood transfusions delivered in the home helped to avoid unnecessary hospital admissions and improved QoL of patients & carers.  |
| <b>Hasson et al. (2008)</b>         | To explore link nurses' views and experiences regarding development, barriers and facilitators to the implementation of the role in palliative care in the nursing home. | Nursing homes (n=10); link nurses (n=14)  | Qualitative  | Focus groups          | n/a | The link nurses system shows potential to enhance palliative care within nursing homes. Facilitators to implementing the role included external support, monthly meetings, access to a resource file and peer support among link nurses themselves. Barriers included lack of management support, a transient workforce and the lack of adequate preparations for link nurses. |

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| <b>Lucey, M. et al. (2008)</b>   | To (a) perform a systems analysis of the process by which patients under the care of a specialist palliative home care obtained medications and factors that delay this process & (b) document the prevalence of each factor in the system causing delay. | Specialist palliative home care service; GPs (n=111); pharmacists (n=57); patients (n=22) | Mixed methods | Questionnaire; prospective observational study | n/a | Main factors causing delay were: medications not being in stock in pharmacies, medications not being available on state reimbursed schemes and inability of patients and carers to courier medications.  |
| <b>Twomey, F. et al. (2008)</b>  | To compare the ability of 5 professional groups to estimate the survival of patients admitted to a SPC unit.  | Clinicians (n=40)   | Quantitative  | Survey   | n/a | No group accurately predicted the length of patient survival more than 50% of the time. Nursing and junior medical staff were most accurate while care assistants were least accurate. When in error, senior clinical staff tended to under-estimate survival. |
| <b>Waldron, M. et al. (2008)</b> | To assess the palliative care education received and consequently cascaded by designated nursing home staff.  | Private nursing home; nursing staff (n=30)  | Quantitative  | Survey   | n/a | There was a high satisfaction with course content, facilitation and benefits accrued from participation. Many respondents had not commenced cascading training within their nursing homes to lack of time and competing mandatory demands.                     |

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| <b>Bailey, M.E. et al. (2007)</b> | To develop and evaluate guided group reflective practice in   | Hospice; palliative care nurses (n=8)                                       | Qualitative | Interviews                          | n/a | Group evaluation of the project is discussed under the following themes: understanding the process of reflective practice; the value of keeping a reflective diary; guided group reflection and moving forward. The introduction of guided reflection for palliative care nurses has afforded both the facilitators and the participants an opportunity to meet away from the clinical environment, and to work together, finding fresh insights to inform practice. |
| <b>McIlfatrick, S. (2007)</b>     | To assess the palliative care needs of patients receiving palliative care from the perspective of patients, informal carers and healthcare professionals. | Patients & lay carers (n=24); professional palliative care providers (n=52) | Qualitative | Individual & focus group interviews | n/a | Professional providers experienced difficulty in defining the term palliative care. Difficulties in communication and information exchange, and fragmented co-ordination between services were identified. The main areas of needs identified by all participants were social and psychological support; financial concerns; and the   |

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|                                     |  |                                  |              |                        |     | need for choice & info. All participants considered that there was inequity between palliative care service provision for patients with (non) cancer diseases.  |
| <b>McLaughlin, D. et al. (2007)</b> | To explore the bereaved caregivers' experience of the Hospice at Home service delivered in one region of the UK.   | Caregivers (n=128)               | Quantitative | Questionnaire          | n/a | Generally positive experiences of the Hospice at Home service. A number of suggestions were made relating to increased awareness of the service, training for staff, coordination of service delivery and bereavement support. Limitations of the study noted.        |
| <b>Robinson, F. et al. (2007)</b>   | To explore attitudes and experiences of doctors and nurses regarding cardiopulmonary resuscitation for patients with end stage illness in an acute hospital. | Acute hospital (n=16 clinicians) | Qualitative  | Focus group interviews | n/a | Variation among participants in terms of how resuscitation policy and DNAR are both interpreted. Interprofessional conflict reported due to different approaches to patient care as well as some cultural differences. Ongoing staff training and education required. |

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| <b>Kernohan, G. et al. (2006)</b>    | To explore patient satisfaction on medical, social and therapeutic out-patient palliative care services in a hospice setting.   | Hospice day care centre (n=1); Patients (n=26) | Mixed methods | Chart review; Questionnaire | n/a | Generally positive findings. A number of suggestions for new service activities were made, and the need for education of multi-professional team members was recognised. Recognised that day hospice allowed respite care for the family.   |
| <b>McIlfatrick, S. et al. (2006)</b> | To explore the nurses' experience of a day hospital chemotherapy service in an acute general hospital & how this compared with their experience of working in an inpatient setting. | Nurses (n=10)                                  | Qualitative   | Individual interviews       | n/a | Nurses viewed their experience of a chemotherapy day hospital as having both positive and negative dimensions. The positive dimensions included an increased sense of autonomy and the challenge of developing new skills, while the negative dimension included a perceived decrease in their caring role. There is a need to achieve a balance between delivering a clinical role while maintaining the centrality of the nurse-patient relationship. |

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| <b>Mc Nicholl, M.P. et al. (2006)</b>    | To describe the experience of staff in one acute hospital in Northern Ireland who adapted the Liverpool Care Pathway for the dying patient.   | Acute hospital                          | Qualitative / audit? | Observational case study?                   | n/a | Key finding is that as long as patients continue to meet the criteria for LCP, some may be on the care pathway for more than the recognised average of Two days.  |
| <b>Whittaker, E. (2006)</b>              | To explore the level of palliative care knowledge among qualified staff delivering end-of-life care in nursing home settings, to inform the development of an appropriate education and training programme. | Nursing homes (n=48); 227 nursing staff | Quantitative         | Questionnaire                               | n/a | Results indicated that less than half the sample had obtained formal training in the area of pain assessment and management and less than a quarter had obtained training in non-malignant conditions. Registered nurses in this study reported a lack of awareness of palliative care principles or national guidelines. Qualified nursing home staff agreed that palliative care is a valuable model for care in their setting. |
| <b>THEME: SPECIFIC GROUPS (CHILDREN)</b> |   |   |                      |   |     |   |
| <b>Nicholl, H. et al. (2012)</b>         | To explore mothers' experiences of caring for a child with complex needs  | Mothers (n=17)                          | Qualitative          | Individual interviews; documentary analysis | n/a | Caring for a child with complex needs involves the delivery of care in an inside world of the home, the world outside the home, and a "going-between" world. Caregiving were found to be 1 of 8 closely linked  |

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|  |   |   |             |                       |     | dimensions and included the following 4 categories: normal mothering, technical caregiving, pre-emptive caregiving, and individualised caregiving.  |
| <b>Price et al. (2012)</b>               | To examine the experiences of bereaved parents concerning the care provided to children who died from cancer compared to those who died from a non-malignant condition. | Bereaved parents of children who died, recruited through two regional centres | Qualitative | Individual interviews | n/a | Typically, parents of children with cancer considered care at the end of life as well resourced and responsive to their and their child's needs. In contrast, parents of children with non-malignant conditions reported under-resourced and inadequately responsive services. Although both groups of parents called extensively on military metaphors such as 'battle', 'fight' and 'struggle', the focus of their respective energies was different. In the one case the adversary was disease and illness; in the other it was service providers and service provision. |
| <b>Gilrane-McGarry, U. et al. (2011)</b> | To identify and describe the bereavement experiences of   | Grandparents (n=17)   | Qualitative | Individual interviews | n/a | Grandparents experience double and 'cumulative pain'. There is a need for the   |

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|                                | grandparents following the death of a grandchild and to explore their needs and supports throughout this experience.   |   |             |                       |     | complexity and intensity of the grief felt by bereaved grandparents to be recognised, acknowledged, and supported by health professionals and society.  |
| <b>Price, J. et al. (2011)</b> | To explore the experiences of recently bereaved parents.   | Parents (n=25)  | Qualitative | Interviews            | n/a | Four analytically distinct processes were identified in the responses of parents to the death of a child. These are referred to as 'piloting', 'providing', 'protecting' and 'preserving'. Regardless of individual circumstances, these processes were integral to all parents' coping, enabling an active 'doing' for their child and family throughout the trajectory of their child's illness and into bereavement. |
| <b>Quinn, C. et al. (2011)</b> | To elicit the views and experiences of palliative care CNSs working in the community with children and families requiring palliative care from a service primarily planned for adults. | Community palliative care clinical nurse specialists (CNSs) | Qualitative | Focus group interview | n/a | Four key themes emerged: gaining access to the child and family; role complexities; pressures of caring; and support strategies. Provision of community children's palliative care by CNS is complex.   |



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| <b>Kiernan, G. et al. (2010)</b>   | To investigate physicians' and nurses' perceptions of psychosocial issues in pediatric oncology including their awareness of the psychosocial impact of childhood cancer on families and their knowledge and views of psychosocial interventions. | Physicians (n=6) and nurses (n=4)  | Qualitative (phenomenological approach) | Individual interviews | n/a | Despite a lack of formal training in psychosocial issues, professionals identified a number of psychosocial issues associated with childhood cancer including effects for family members. They recognised the value of formal intervention for children, families and themselves. Findings suggest the need for more formal training on psychosocial issues for medical and nursing staff.                                 |
| <b>McCloskey, S. et al. (2010)</b> | To explore the experiences of stress in nurses providing children's palliative care.  | Children's hospice nurses (n=9), community children's nurses (n=7), children's nurse specialists (n=2) | Qualitative                             | Focus groups          | n/a | Four core themes emerged: work demands (emotional load, ethical conflicts, constraints to the delivery of good care, limited resources, administration & living and working in the same community); relationships; maintaining control; and support and roles (managerial support and role ambiguity). Implications for how individuals and organisations may reduce impact for nurses in various settings are considered. |

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| <b>Meyler, E. et al. (2010)</b> | A systematic review of family-based psychosocial interventions with pediatric oncology populations.                                  | Studies (n=21) meeting inclusion criteria  | Systematic review | n/a  | n/a | Findings illustrate that multiple family members are integrated into interventions for childhood cancer in several ways. Considerable variations were observed regarding the family member combinations targeted and the intervention modalities employed. A minority of interventions met the criteria for empirically validated treatments; however; evidence of beneficial outcomes was observed across the majority of interventions reviewed. |
| <b>Clarke, J. et al. (2007)</b> | To explore the experiences of professional carers' in providing pediatric palliative care to children with life-limiting conditions. | Professional groups providing hospital and/or community-based care in the voluntary and statutory areas. | Mixed methods     | Questionnaire; focus group interviews (n=15) | n/a | The humanity of professional carers' caring reality may be articulated through three themes: clarity of definition and complexity of engagement; seeking to deliver a palliative care service; and the emotional cost of providing palliative care. Further analysis highlights a work-life experience of skilled and emotional engagement with  |

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|                                       |  |   |               |   |     | children, and their parents, in complex processes of caregiving and decision-making.   |
| <b>McCluggage, H.L. et al. (2006)</b> | To identify the symptoms experienced by life-limited children which cause anxiety to staff working in children's hospices. | Hospice administrators (n=10); nurses (n=18); doctors (n=10)  | Quantitative  | Questionnaire                                     | n/a | More than 70% of all staff groups felt that identifying the symptom correctly caused more anxiety than treating identified symptoms. Doctors & nurses perceive seizures, pain management & vomiting as the most troublesome symptoms for children with life-limiting conditions. |
| <b>O'Leary, N. et al. (2006)</b>      | To examine the experience of an adult palliative care service providing palliative care to children.                       | Case review of children (n=20); questionnaires (11 nurses; 3 medical staff); focus group (n=8 nursing/ medical staff) | Mixed methods | Case review; Questionnaire; Focus group interview | n/a | Main themes highlighted were staff competence, staff stress, uncertainty of prognosis, resource implications and co-operation with other teams. Some key challenges highlighted for an adult palliative care team providing paediatric palliative care.                          |

| THEME: SPECIFIC GROUPS (COPD)  |  |   |             |            |     |  |
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| <b>Hynes, G. (2012)</b>        | To explore the experiences of informal caregivers providing care in the home to a family member with COPD. | Family caregivers (n=11) of individuals with COPD | Qualitative | Interviews | n/a | Six core themes emerged including 'then and now' reflecting caregivers' sense of loss and enmeshment with the illness experience and burden. The caregivers' experience of illness burden included symptom, cultural and lifeworld meanings. Relationships between formal health care and healthcare professionals were rendered difficult by their perceived failure to look beyond acute exacerbations as discrete events rather than integral to the illness trajectory as a whole. |
| <b>Casey, D. et al. (2011)</b> | To develop a structured education programme for clients with COPD.   | COPD patients (n=16); health professionals (n=25) | Qualitative | Interviews | n/a | Findings indicate that nurses working in primary care have an important role in informing the development of SEPRP (Structured Education Pulmonary Rehabilitation Programme) as well as having a key role in their delivery. They have the potential to  |

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|                                 |  |   |             |                                       |     | work in empowering ways with COPD patients and the PRINCE (Pulmonary Rehabilitation In Nurse-led Community Environments) SEPRP is just one example of how this can be put into practice.   |
| <b>Hasson, F. et al. (2009)</b> | To explore the experiences of palliative care that bereaved carers had while providing care to a dying loved one with COPD.                          | Carers with advanced COPD (n=9)             | Qualitative | Individual interviews                 | n/a | Three themes emerged: the impact of the caring experience, the lack of support services, and end-of-life and bereavement support. Carers experienced carer burden, lack of support services, need for palliative care, and bereavement support.  |
| <b>Spence, A. et al. (2009)</b> | To explore professionals' perceptions of palliative care and facilitators and barriers to the delivery of such care for patients with advanced COPD. | Health and social care professionals (n=23) | Qualitative | Individual and focus group interviews | n/a | Care of patients with COPD is focused upon the management of symptoms, with emphasis focused predominantly on an acute model of care. Key barriers towards the delivery of palliative care included the reluctance to negotiate end-of-life decisions and a perceived lack of understanding among patients |

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|                                 |  |   |             |                       |     | and carers regarding the illness trajectory. Consequently the delivery of palliative care was viewed as a specialist role rather than an integral component of care.  |
| <b>Hasson, F. et al. (2008)</b> | To explore the potential for palliative care among people living with advanced chronic obstructive pulmonary disease (COPD). | Patients with a diagnosis of advanced COPD (n=13) | Qualitative | Individual interviews | n/a | Participants raised concerns about the unknown trajectory of the illness and reported unmet palliative care needs with poor access to palliative care services. Research suggests that needs for palliative care be extended to all (regardless of diagnosis), with packages of care developed to target specific needs.                |
| <b>Spence, A. et al. (2008)</b> | To explore the specific care needs of informal caregivers of patients with advanced COPD.                                    | Active family caregivers (n=7)                    | Qualitative | Individual interviews | n/a | Family caregivers provide direct care with little support and assistance. There were knowledge deficiencies among caregivers relating to the COPD illness trajectory and little awareness of the potential of palliative care. Family caregivers need social and professional support/interventions while caring for a patient at home. |

| THEME: SPECIFIC GROUPS (DEMENTIA)  |   |   |              |                             |  |  |
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| <b>Connolly, S. et al. (2012)</b>  | To estimate the economic and social costs of dementia in Ireland in 2010  | People with dementia                                | Quantitative | Database analysis           | n/a  | The total baseline annual cost was found to be over €1.69 billion, 48% of which was attributable to the opportunity cost of informal care provided by family and friends and 43% to residential care.  |
| <b>Gallagher, D. et al. (2011)</b> | To examine the relationship between self-efficacy for dementia-related tasks and symptoms of burden and depression in caregivers. | 84 patient/caregiver dyads with Alzheimer's disease | Quantitative | Assessments; questionnaires | DSM-R IV; NINCDS-ADRDA criteria; Mini Mental State Examination; Eysenck personality questionnaire; Zarit Burden Inventory; CESD-10; Lubben social network scale; Neuropsychiatric Inventory (NPI); Disability Assessment for Dementia scale (DAD); 10-item self-efficacy scale; Brief COPE | 33% of caregivers reported significant depressive symptoms. Caregiver burden was predicted by self-efficacy for symptom management, neuroticism, patient function and neuropsychiatric symptoms while caregiver depression was predicted by self-efficacy for symptom management, caregiver educational level, neuroticism, emotion-focused coping, dysfunctional coping and patient function. |

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| <b>Pierce, M. et al. (2012)</b>               | Planning dementia services: New estimates of current and future prevalence rates of dementia in Ireland. (paper provides new estimates of dementia prevalence at a national and local level in Ireland).   | People with dementia  | Quantitative  | Database analysis         | n/a   | It is estimated that there were 41,740 people with dementia in Ireland in 2006. Estimates show that there are clear regional differences in prevalence of dementia across Ireland.        |
| <b>THEME: SPECIFIC GROUPS (HEART FAILURE)</b> |  |   |               |                           |   |   |
| <b>Hughes, C. et al. (2012)</b>               | To determine the dietary adequacy of CHF patients compared with Dietary Reference Values, to compare the nutritional intake and status of CHF patients to a healthy comparison group, and finally to determine whether nutritional intake and status depended on New York Heart Association (NYHA) functional class. | Patients with chronic heart failure (n=39) & a comparison group of health participants (n=27) | Quantitative  | Assessments               | n/a   | Overall 73% of the CHF patients were consuming less than recommended energy intakes, and more than 50% of these patients were also consuming less than recommended vitamins and minerals. |
| <b>O'Leary, N. et al (2009)</b>               | A comparative study of the palliative care needs of heart failure and cancer patients.   | 50 HF patients (n=50); cancer patients (n=50)   | Mixed methods | Interviews; questionnaire | Nottingham Extended Activity Daily Living Scale | Both patient cohorts were statistically indistinguishable in terms of symptom burden, emotional wellbeing, and  |



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|                                    |   |  |             |                       | (NEADL);<br>Edmonton<br>Symptom<br>Assessment<br>Scale (ESAS);<br>HADS; Short<br>Form-36 | quality-of-life scores. HF patients had good access to community and social support. HF patients particularly valued the close supervision, medication monitoring, ease of access to service, telephone support, and key worker provided at the HF unit. A small subset of patients had unmet PC needs. |
| <b>Ryan, M. et al. (2009)</b>      | To describe patients' experiences of living with advanced heart failure   | Patients with advanced (NYHA classes III–IV) heart failure (n=?) | Qualitative | Individual interviews | n/a  | Four main themes emerged: Living in the Shadow of Fear; Running on Empty; Living a Restricted life; and Battling the System. The experience of living with advanced heart failure was described as a fearful and tired sort of living characterised by escalating impotence and dependence.             |
| <b>THEME: SPECIFIC GROUPS (ID)</b> |   |  |             |                       |  |   |
| <b>Mc Evoy, J. et al. (2012)</b>   | To investigate how individuals with ID understand and explain death and make sense of life without the deceased | Individuals with intellectual disabilities (n=34)                | Qualitative | Interviews            | n/a  | Death comprehension was positively correlated with cognitive ability and adaptive functioning. While cause of death was predominantly associated with illness and old   |

age, participants viewed death as final and understood that all living things die. The role of religious beliefs was also found to be important for many participants. The results support earlier findings that suggest people with ID have only a partial understanding of the concept of death leaving them vulnerable to factually incorrect thoughts.

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| <b>McCarron, M. et al. (2011)</b> | To better describe the role and timing of palliative care in supporting persons with intellectual disabilities and advanced dementia (AD). | Intellectual disability services (n=6); staff (n=?) | Qualitative | Focus groups | n/a | Specialist palliative care staff recognised that person-centred care delivered in intellectual disability services was consistent with palliative approaches, but staff in intellectual disability services did not consider advanced dementia care as 'palliative care'. Both groups were unsure about the role of palliative care at early stage of dementia but appreciated specialist palliative care contributions in addressing pain and symptom management challenges. |
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| <b>Ryan, K. et al. (2011)</b>     | To explore paid carers' perspectives when caring for people with ID at the end of life.   | Various settings (see Ryan, K. et al., 2011); health care professionals (n=64) | Qualitative   | Focus group interviews (n=16)          | n/a | Study describes issues which contribute to the development of staff stress when providing palliative care (e.g. situations when end of life care decision making was challenging, when staff felt 'pushed out' by relatives, and when staff did not have sufficient support or time to provide care or mourn the loss of service users.             |
| <b>McCarron, M. et al. (2010)</b> | To understand staff perceptions of critical issues in caring for persons with intellectual disability (ID) and advanced dementia. | Persons with ID and advanced Dementia  | Qualitative   | Focus group interviews                 | n/a | Views of specialist palliative care staff.  |
| <b>Ryan, K. et al. (2010)</b>     | To describe the experience, confidence and attitudes of staff to the provision of palliative care to people with ID.              | Staff from ID and palliative care services (n=261)                             | Mixed methods | Questionnaire & focus group interviews | n/a | Both palliative care and intellectual disability services staff lacked confidence in their ability to provide palliative care. Staff were challenged by perceived 'differences' and 'difficulties' in the provision of care. They endorsed a partnership approach to care but a shared desire to cooperate did not predict effective collaboration. |

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| <b>Fahey-McCarthy, E. (2009)</b> | To understand care concerns with respect to supporting persons with ID and advanced dementia, and to develop, deliver, and evaluate an educational intervention with staff in ID settings and specialist palliative care services | Intellectual disability services (n=6); specialist palliative care provider (n=1) | Qualitative  | Focus groups | n/a                                    | Data analysis informed development of an educational intervention. Staff indicated that the educational intervention was highly valued and addressed key training concerns. They agreed that the training supported “aging in place,” and the preparation for a “good death” including support for staff, peers, and family in their grief and bereavement. An educational intervention in the form of a trainer manual was produced to support cross-service system in-service training on issues of addressing advanced dementia in persons with ID. |
| <b>Guerin, S. et al. (2009)</b>  | To describe and gather preliminary psychometric data for a version of the Inventory of Complicated Grief for people with ID (CGQ-ID).   | Patients with ID (n=76)   | Quantitative | Assessments  | CGQ-ID; The Index of Social Competence | The final scale and subscales (Separation Distress and Traumatic Grief) showed very good internal and inter-rater reliability and distinguished between the two groups (i.e. half experienced a parental bereavement within the last 2 years and half who had not). Findings suggest that the CGQ-   |

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|                                  |  |  |              |               |   | ID is suitable for identifying complicated grief-type symptoms among adults with ID, further research required.  |
| <b>MacHale, R. et al. (2009)</b> | To explore staff perceptions of service users' conceptualisations of death, reactions to bereavement, required levels of support and staff confidence in providing post-bereavement support. | Service users with ID (n=32); Care staff (n=42)  | Quantitative | Survey        | Index of Social Competence; Staff Attitude Questionnaire (STAQ)   | Staff believed that service users had a good concept of death, though staff tended to overestimate levels of understanding and possibly underestimate the potential dysfunctional behaviour post-bereavement. Although staff expressed confidence in their ability to recognise grief symptoms, they were less confident in their ability to provide post-bereavement support. |
| <b>Dodd, P. et al. (2008)</b>    | To examine the occurrence of symptoms of complicated grief, and to explore the relationships between complicated grief and bereavement experience  | Individuals with an ID (n=76) who had experienced a parental bereavement within the previous 2 years | Quantitative | Questionnaire | Complicated Grief Questionnaire for People with ID; Bereavement History Questionnaire (adapted); Index of Social Competence | Study revealed that bereaved individuals with ID experience complicated grief symptoms following the death of a parent, with one-third of the bereaved group experiencing 10 or more clinically apparent symptoms. In addition, complicated grief symptoms were more likely to occur with  |

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|   |   |   |               |                         |  | higher rates of bereavement ritual involvement. These findings have both clinical and research implications.   |
| <b>Reynolds, S. et al. (2008)</b>         | To examine the impact of a staff-training program on knowledge and confidence in supporting people with intellectual disabilities (ID) at the time of bereavement | Intellectual disability support service; staff (n=33) | Quantitative  | Survey                  | n/a  | Over the 4 weeks, there was a significant increase in confidence among the training group, with no comparable changes in the control group. Neither group showed significant changes in general support or job satisfaction. Findings suggest that the training significantly increased staff members' confidence in their ability to respond to the challenges of support service users during bereavement. |
| <b>THEME: SPECIFIC GROUPS (Malignant)</b> |   |   |               |                         |  |  |
| <b>Roulston, A. et al. (2012)</b>         | A pilot study to evaluate an outpatient service for people with advanced lung cancer.   | Patients (n=4)  | Mixed methods | Interviews; assessments | Eastern Cooperative Oncology Group Performance Status Rating (ECOG-PSR), the Hospital Anxiety and Depression | Many patients with lung cancer are symptomatic from diagnosis, and quality of life (QoL) may be maximised through the use of specialist palliative care in parallel with other treatments. Study found that preconceived ideas about   |

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|                                    |   |   |                                |     | Scale (HADS), the EQ-VAS, and the EQ-5D | a 'Breathing Space' attendance were replaced with positive impressions. Anxiety and EQ-VAS scores improved for all patients, and depression scores improved for four of the five patients, although no tests of significance were made. The qualitative data indicated that there were psychosocial benefits to attending the clinic.            |
| <b>Donohoe, C.L. et al. (2011)</b> | Cancer cachexia: mechanisms and clinical implications.                            | n/a   | Systematic review              | n/a | n/a                                     | Cachexia is compounded by anorexia and the relationship between these two entities has not been clarified fully. Inconsistencies in the definition of cachexia have limited the epidemiological characterisation of the condition and there has been slow progress in identifying therapeutic agents and trialling them in the clinical setting. |
| <b>Donohoe, C.L. et al. (2011)</b> | To examine the impact of young age on outcomes in esophageal & junctional cancer. | Patients (n=2129) diagnosed with esophageal | Retrospective case note review | n/a | n/a                                     | Younger patients (aged less than 50 years) were more likely to be treated with curative rather than palliative   |

| carcinoma                        |  |                  |   |             |               | intent. Multivariate analysis revealed independent factors related to difference in survival included sex, age, advanced T stage, and nodal metastases.  |
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| <b>Hegarty, J. et al. (2010)</b> | To compare the beneficial and harmful effects of radical prostatectomy (RP) versus watchful waiting (WW) for the treatment of localised prostate cancer. |                  | Systematic review                       | n/a         | n/a           | Two trials met the inclusion criteria. After 12 years of follow up, the trial results were compatible with a beneficial effect of RP on the risks of overall mortality, prostate cancer mortality and distant metastases compared with WW but the precise magnitude of the effect is uncertain. Compared to WW, RP increased the absolute risks of erectile dysfunction and urinary leakage (based on self-administered questionnaires). |
| <b>Curran, D. et al. (2009)</b>  | To investigate the quality of life of palliative chemotherapy naive patients with advanced adenocarcinoma of the stomach or esophagogastric junction     | Patients (n=333) | Quantitative (Randomised Control Trial) | Assessments | EORTC QLQ-C30 | The time-to-progression for IF and CF was 5.0 and 4.2 months respectively. The overall compliance rates for QL questionnaire completion were 60 and 56% in the IF and CF arms, respectively. Significant treatment   |



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|                                    | treated with irinotecan combined with 5-fluorouracil and folinic acid: results of a randomised phase III trial. |   |                                |             |  | differences were observed. There was a trend in favour of IF over CF in time-to-progression. The IF group also demonstrated a better safety profile than CF and a better QL on a number of multi-item scales, suggesting that IF offers an alternative first-line platinum-free treatment option for advanced gastric cancer. |
| <b>Donohoe, C.L. et al. (2009)</b> | Palliative endoscopic trans-anal resection (ETAR) of advanced rectosigmoid carcinoma.                           | Patients (n=14)                         | Retrospective case note review | n/a         | n/a  | ETAR provides a convenient and safe method of palliation for patients with local symptoms of advanced rectosigmoid carcinoma.   |
| <b>Mullane, M. et al. (2009)</b>   | To validate the Demoralization Scale in a sample of 100 Irish advanced cancer patients.                         | In-patients with advanced cancer (n=76) | Quantitative                   | Assessments | Demoralization Scale; Beck Depression Inventory; Patient Health Questionnaire; Beck Hopelessness Scale; Schedule of Attitudes toward | The findings show that in an Irish palliative care context, demoralization is not differentiated from depression. Additional factor analytic studies are needed to validate the Demoralization Scale.   |

|   |   |  |  |               | Hastened Death;<br>McGill Quality of<br>Life<br>Questionnaire;<br>Hunter's<br>Opinions and<br>Personal<br>Expectations<br>Scale. |  |
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| <b>Timon, C. et al. (2006)</b>                | To document the outcome of patients deemed at initial diagnosis to be appropriate for palliative care.            | Patients (n=286) with head and neck mucosal squamous cell carcinoma (HNMSCC) | Retrospective case note review & database analysis | n/a           | n/a  | One in five patients presenting with HNMSCC were deemed appropriate for palliative care at initial presentation and survived less than six months after diagnosis. More than one-third required surgical intervention, and 29 per cent never returned home.                              |
| <b>THEME: SPECIFIC GROUPS (Non-malignant)</b> |   |  |  |               |  |  |
| <b>O'Leary, N. et al. (2008)</b>              | To describe Irish Specialist Palliative Care (SPC) services' provision for, and attitudes to non-cancer patients. | Clinical managers (n=65)   | Quantitative                                       | Questionnaire | n/a  | There is a mismatch between availability of palliative care services for non-cancer patients and uptake. Perceived barriers to service provision include unpredictable nature of non-cancer disease trajectory, issues with referral criteria and lack of non-cancer specific expertise. |

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| <b>Fitzsimons, D. et al. (2007)</b>          | To explore the palliative care needs of patients with a non-cancer diagnosis from the perspectives of the patient, their significant other and the clinical team responsible for their care. | Regional hospital; Patients (n=18) diagnosed with end-stage heart failure, renal failure or respiratory disease. | Mixed methods | Individual interviews (n=18 patients and separately n=17 significant others); focus group (n=18 clinical team) | Short Form 36 (SF36); Hospital and Anxiety Depression Scale(HADS) Questionnaire | Deteriorating health status led to decreased independence, social isolation and family burden. General resources and support were perceived as lacking. All participants expressed concerns regarding the patients' future and some patients described feelings of depression or acceptance of the inevitability of death. An earlier and more effective implementation of the palliative care approach is necessary if the needs of patients in the final stages of chronic illness are to be adequately addressed. |
| <b>THEME: SPECIFIC GROUPS (Older people)</b> |  |  |               |  |   |  |
| <b>Ní Chróinín, D. et al. (2011)</b>         | To investigate the effect of the death of older Irish persons on patients and staff in a 320-bed long-stay elderly care facility.  | Patients (n=7); staff (n=3)  | Qualitative   | Individual interviews  | n/a   | Participants described feelings of loss, in adequacy, and the desirability for patients and family to have privacy during the dying phase. The researchers identified a four-stage model to describe the fellow patient grief reaction: (1) remembrance; (2)   |

|                                    |  |  |               |                    |     |  |
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|                                    |  |  |               |                    |     | reflection; (3) religiosity; and (4) relations. Findings highlight the need for bereavement care programmes in elderly care units.   |
| <b>Payne, S. et al. (2009)</b>     | To examine the end-of-life care experiences of older people in acute care hospitals and long-stay institutions in Ireland.                         | Hospitals and long staff facilities (n=592); health care workers (n=35); Older patients (n=30) | Mixed methods | Survey; interviews | n/a | Proposed a new model and framework to guide the delivery of palliative and end-of-life care to older people in institutions. Proposed a conceptual model for understanding older people's experiences of transitions near the end of life. |
| <b>McDonnell, M. et al. (2009)</b> | To identify the palliative care education needs of registered general nurses (RGNs) and health-care assistants (HCAs) working in care of the older | HSE older care units; RGNs (n=205); HCAs (n=154)   | Quantitative  | Questionnaire      | n/a | Specific education needs identified by RGNs and HCAs. Significant difference between RGNs and HCAs' level of understanding of palliative care. Study identified the need to develop separate education programmes.                         |

| THEME: SPECIFIC GROUPS (Parkinson's) |  |   |             |                                       |     |   |
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| <b>McLaughlin, D. et al. (2011)</b>  | To explore the caring experience of relatives with Parkinson's Disease.  | Informal family caregivers (n=26)                     | Qualitative | Individual interviews                 | n/a | Results highlight the widespread burden of providing care on the emotional and physical health of the caregivers. The financial implications for providing care were outlined. From the point of diagnosis, carers did not feel health professionals integrated them within the caring journey. Since diagnosis, carers commented on the lack of continued and coordinated care plans for relatives, resulting in symptoms being mismanaged and care opportunities for relatives and carers missed. |
| <b>Waldron, M. et al. (2011)</b>     | To examine the social worker's role in the delivery of palliative care to clients with Parkinson's disease (PD). | Community and hospice settings; Social workers (n=13) | Qualitative | Individual and focus group interviews | n/a | Differing perceptions of palliative care emerged. Negative associations of palliative care were identified. Very few clients with PD are referred to specialist palliative care specifically for management of their symptoms, which must   |

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|                                  |  |   |             |                        |     | prevent holistic care. Social workers have an important yet underdeveloped role in identifying and addressing palliative care needs.   |
| <b>Hasson, F. et al. (2010)</b>  | To explore former carers' lived experiences of palliative and end-of-life care.  | Family caregivers (n=15) of patients who had died with Parkinson's disease.     | Qualitative | Individual interviews  | n/a | Lack of communication, knowledge and coordination of services resulted in many people caring for someone with PD not accessing specialist palliative care services. Participant's also reflected on the physical and psychological impact of caring in the advanced stage of PD.   |
| <b>Waldron, M. et al. (2010)</b> | To explores the views of allied health professionals in delivering rehabilitation in palliative care to people with Parkinson's disease. | Allied health professional (n=12), from both generalist and specialist settings | Qualitative | Focus group interviews | n/a | Participants viewed palliative care as holistic care, however, the rehabilitation care they provided was impeded by a number of personal and organisational barriers, and negative perceptions. There is a need to educate professionals in the principles of palliative rehabilitation, combined with providing targeted resources to promote shared care and responsibility. |

| THEME: SPECIFIC GROUPS (Same sex couples) |  |  |               |  |     |  |
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| <b>Glacken et al. (2008)</b>              | To explore the grief experience of same sex couples.   | Individuals (n=7) whose partners died from an AIDS/HIV-related illness.  | Qualitative   | Individual interviews  | n/a | Five themes emerged that captured the bereavement experience: tacit acknowledgement; sculpting the distress; multiple losses; seeking support; and journeying anew. Many of the participants experienced disenfranchised grief. Health care professionals need to consider their approach to people who identified themselves as gay or lesbian, if they are to provide support structures (formal and informal) to meet their unique needs. |
| THEME: SPECIFIC GROUPS (Travellers)       |  |  |               |  |     |  |
| <b>McQuillan, R. et al. (2007)</b>        | To explore the indigenous ethnic minority group, Irish Travellers and palliative care services in Ireland. | Specialist palliative care service providers; Travellers (5 groups, n=?) | Mixed methods | Questionnaire (n=81); individual and focus group interviews (n=16) | n/a | Common themes emerged- low use of palliative care services by Travellers, concerns of both Travellers and specialist palliative care staff about Travellers education and literacy ability to deal with health care services, the role of the family,  |

and demonstrative expressions of grief by Travellers. Both sides were aware of their lack of information about the other.

#### THEME: SPIRITUALITY

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| <b>Bailey, M.E. et al. (2009)</b> | To describe nurses' experiences of delivering spiritual support in a palliative care setting. | Specialist palliative care nurses (n=22) | Qualitative   | Individual interviews      | n/a | Five sub-themes: understanding spirituality; the art of nursing in spiritual care; education and learning; the challenges of spiritual caring; and the dimensions of time. The challenges of assessing spiritual needs were also reported. Participants described the creation of a spiritual tapestry that 'weaves' together care and compassion with skills & knowledge in their nursing practice. |
| <b>Kernohan, G. et al. (2007)</b> | To assess patients' spiritual needs and perceptions of a chaplaincy service.                  | Patients (n=62)                          | Mixed methods | Case review; Questionnaire |     | Findings suggest that the Standards for Hospice and Palliative Care Chaplaincy (2003) were useful for assessing and addressing spiritual needs. Participants, of whom 92% had a faith in God   |



or a Higher Being, highlighted their top six spiritual needs as: to have time to think; to have hope; to deal with unresolved issues; to prepare for death; to express true feelings without being judged; and to speak of important relationships. Majority of participants felt that their spiritual needs had been met.

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| <b>MacConville, U. (2006)</b> | To "map" understandings of religion and spirituality in an Irish palliative care setting |  | Qualitative | a cartographic approach | n/a | Aspects of religion and spirituality have been explored within a multi-layered Irish cultural setting to reveal a complex landscape--a landscape that is changing but which draws upon the past in shaping the present. |
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#### THEME: SYMPTOMS (CACHEXIA)

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| <b>Reid, J. et al. (2009)</b> | To investigate the tensions over food that exists between patients with advanced cancer with cachexia and their families. | Patients with advanced cancer living with cachexia (n=8); family members (n=8) | Qualitative (Heideggerian phenomenologic approach) | Individual interviews | n/a | Findings highlight the anxiety that surrounds eating and the distress it causes to patients and their families. This strain can escalate into arguments over food, causing negative repercussions for patients and their family members. |
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| <b>Reid, J. et al. (2009)</b>     | To investigate the perceptions of patients and family members with regard to care received for cancer cachexia. | Patients (n=15) with advanced cancer who had primary cachexia & family members (n=12) | Qualitative  | Domiciliary interviews | n/a   | A major finding was 'lack of response from health care professionals' in relation to cancer cachexia management. Participants reported wanting three things from healthcare professionals: profound weight loss acknowledged; information about it and why it was happening; and interventions to deal with it.  |
| <b>THEME: SYMPTOMS (DELIRIUM)</b> |   |   |              |                        |   |  |
| <b>Meagher, D. et al. (2012)</b>  | To examine features that characterise subsyndromal delirium and persistent delirium over time                   | Adults with DSM-IV delirium (n=100)   | Quantitative | Assessments            | Delirium Rating Scale- Revised-98 (DRS-R98) and Cognitive Test for Delirium (CTD) | Full syndromal delirium was significantly more severe than subsyndromal delirium for DRS-R98 thought process abnormalities, delusions, hallucinations, agitation, retardation, orientation, attention, and short- and long-term memory items, and CTD attention, vigilance, orientation and memory. Persistent full syndromal delirium had greater disturbance of DRS-R98 thought process abnormalities, delusions, agitation, orientation, attention, and |

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|                                  |   |  |              |                          |  | short- and long-term memory items, and CTD attention, vigilance and orientation.  |
| <b>Leonard, M. et al. (2011)</b> | To study phenomenological and neuropsychological profile across motor variants of delirium in a palliative care unit.   | Patients meetings DSM-IV criteria for delirium (n=100) | Quantitative | Standardised assessments | DRS-R-98; Cognitive Test for Delirium (CTD); Delirium Motor Checklist (DMC); Delirium Motor Subtype Scale (DMSS); Ease of Ward management Scale (EOWM); Delirium Etiology Rating Checklist | Motor variants in delirium have similar cognitive profiles, but mixed cases differ in expression of several non-cognitive features. Similar to previous findings, patients with both hyperactive and mixed subtypes received greater attention and antipsychotic medication than their hypoactive counterparts. |
| <b>Godfrey, A. et al. (2010)</b> | To determine the use and feasibility of accelerometry-based monitoring and to examine a discrete multi-resolution signal analysis technique to determine motoric subtypes in patients with DSM-IV delirium. | Patients (n=34)  | Quantitative | Assessments              | (24-h accelerometer-based monitoring)  | Of the 34 patients included, 25 met criteria for DSM-IV delirium while 9 were non-delirious comparison subjects with equivalent medical diagnoses receiving treatment in the same setting. It was concluded that accelerometry-based measurement of a delirious cohort within a palliative setting is both a    |

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|                                  |  |   |              |               |   | reliable and feasible method of continuous monitoring. Of the activities performed by the patients, periods of standing proved to be the most discriminatory in determining between each subtype.   |
| <b>Meagher, D. et al. (2010)</b> | To explore the impact of an educational workshop upon attitudes towards pharmacotherapy for delirium.                                      | Health personnel (n=66)   | Quantitative | Questionnaire | n/a   | Most respondents reported psychotropic use with variable frequency. Antipsychotic use was inversely related to perception of supporting evidence. Post-workshop concerns regarding extrapyramidal effects were reduced with a more positive general attitude towards pharmacological interventions. |
| <b>Meagher, D. et al. (2010)</b> | A comparison of neuropsychiatric and cognitive profiles in delirium, dementia, comorbid delirium-dementia and cognitively intact controls. | Adults (n=?) with DSM-IV delirium, dementia, comorbid delirium-dementia and cognitively intact controls | Quantitative | Assessments   | Revised Delirium Rating Scale (DRS-R98) and Cognitive Test for Delirium (CTD) | Delirium and comorbid delirium-dementia groups had comparable DRS-R98 and CTD total scores, which were greater than in dementia or control groups. On the DRS-R98, multiple non-cognitive symptoms, inattention and disorientation were more severe in delirium groups compared with dementia-      |

alone. Patients with dementia differed from both delirium groups on the CTD test of attention. Spatial span backwards was significantly lower in all patients with cognitive impairment (delirium, comorbid delirium-dementia, dementia alone) compared to controls, whereas spatial span forwards distinguished delirium groups from dementia.

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| <b>Leonard, M. et al. (2009)</b> | To assess and compare mood states as they relate to onset of delirium. | Patients (n=100) | Quantitative | Assessments | DSM–IV criteria; HADS; Confusion Assessment Method (CAM); Memorial Delirium Assessment Scale (MDAS); Mini-Mental State Exam (MMSE) | Overall, 51% experienced either major depression or delirium. Most patients with syndromal delirium also met criteria for major depressive illness, and 50% of those with depression had delirium or subsyndromal delirium (SSD). Delirium symptoms were less common in patients with major depression than depressive symptoms in patients with delirium or SSD. |
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| <b>Ryan, K. et al. (2009)</b>    | To determine the sensitivity and specificity of the Confusion Assessment Method (CAM) in diagnosing delirium when used by Non-Consultant Hospital Doctors (NCHDs) working in a specialist palliative care unit. | Pilot study: patients (n=32);<br>main study: patients (n=52) | Quantitative      | Assessments | CAM; Revised Delirium Rating Scale (DRS-R-98); Cognitive Test for Delirium (CTD); Memorial Delirium Assessment Scale (MDAS) | Results suggest that the CAM is a valid screening tool for delirium in the palliative care setting but its performance is dependent on the skill of the operator. NCHDs require a certain standard of training before becoming proficient in its use.  |
| <b>Leonard, M. et al. (2008)</b> | To evaluate factors related to reversibility and mortality in consecutive cases of Diagnostic and Statistical manual of Mental Disorders (4 <sup>th</sup> Ed) delirium occurring in palliative care patients.   | Patients with delirium (n=121)                               | Quantitative      | Assessments | Delirium Rating Scale-Revised-98 (DRS-R-98); Cognitive Test for Delirium (CTD); EOWM  | Findings suggest that reversible delirium is distinguishable by young patient age, less severe cognitive disturbance and absence of organ failure as a cause of delirium. Both the DRS-98 and CTD total scores were worse in the irreversible group. This study along with others identified clinical features that can allow greater precision in prospectively identifying less reversible or 'terminal' delirium. |
| <b>Leonard, M. et al. (2008)</b> | To provide an expert review of delirium in the context of palliative care   | n/a  | Systematic review | Review      | n/a   | Delirium occurs commonly in the context of palliative care where it is likely to cause heightened distress for   |

patients, carers, and families alike, and make interpretation of pain and other symptoms extremely difficult. There is a profound dearth of rigorous studies on delirium in this setting. Ambiguous terminology, varying definitions in internationally recognized classification systems, and failure to use validated assessment tools found.

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| <b>Meagher, D. et al. (2008)</b> | To validate a new approach to motor subtyping in delirium based on data from a controlled comparison of items from three | Cancer patients (n=50) & non-delirious comparison subjects (n=52) | Quantitative | Assessments; questionnaires | Delirium Rating Scale-Revised-98; Cognitive Test for Delirium; Delirium Motor Checklist | The new motor subtyping schema which was derived from existing schema for delirium is relatively simple and based on a checklist that can be rated by nursing staff. Findings suggest that the new scale relates closely to the prevailing concept of delirium than other measures such as DRS-R98 and the Cognitive Test for Delirium. |
| <b>Meagher, D. et al. (2008)</b> | To evaluate delirium phenomena   | Palliative care group   | Quantitative | Assessments                 | 30-item Delirium Motor Checklist (DMC)  | In delirium, motor disturbance was present in 100% by DMC versus 92% by DRS-R98 motor   |

items; the DMC motor items also significantly distinguished delirium from control subjects. Motor subtype classification (hyperactive, hypoactive, mixed, and none) varied among the four methods, with low concordance across all four methods and 76% concordance for pairwise comparisons. The DRS-R-98 identified the most hypoactive delirium cases.

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| <b>Leonard, M. et al. (2007)</b> | To (a) test the applicability of accelerometry in highly morbid patients with delirium; (b) test the correlation of accelerometer readings with observed gross movement; (c) compare quantitative and qualitative motion in motorically defined groups. | Patients (n=3) | Quantitative | Assessments | DRS-R98; Memorial Assessment Schedule; | The procedures were well tolerated and motor presentations were readily distinguished using the accelerometer-based measurements. The system was capable of identifying static versus dynamic activity and the frequency of changes in posture. Electronic motion analysis concurs with observed gross movement and can distinguish motorically defined subtypes according to quantitative and qualitative aspects of movement. |
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| <b>Meagher, D. et al. (2007)</b>   | To investigate the relationship between cognitive and non-cognitive delirium symptoms and test the primacy of inattention in delirium.                  | Individuals (n=100) with delirium | Quantitative              | Assessments | Delirium Rating Scale–Revised–98 (DRS–R98) and Cognitive Test for Delirium (CTD) | Sleep–wake cycle abnormalities and inattention were most frequent, while disorientation was the least frequent cognitive deficit. Patients with psychosis had either perceptual disturbances or delusions but not both. Neither delusions nor hallucinations were associated with cognitive impairments. Inattention was associated with severity of other cognitive disturbances but not with non-cognitive items. CTD comprehension correlated most closely with non-cognitive features of delirium. |
| <b>THEME: SYMPTOMS (NUTRITION)</b> |   |                                   |                           |             |  |  |
| <b>Gray, R.T. et al. (2011)</b>    | To assess the relationship between nutritional factors and 30-day mortality in patients undergoing SEMS insertion for palliation of oesophageal cancer. | Patients (n=53)                   | Retrospective note review | Review      | n/a  | Fifty-six stents were inserted into 53 patients. Thirty (56.6%) patients tolerated an oral diet enhanced with supplement drinks whereas 43.4% patients required more invasive forms of enteral and parenteral support. BMI, calorific intake and swallowing capacity were  |

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|                                 |  |  |              |               |     | not predictors of survival. Invasive nutritional support itself was not predictive of 30-day mortality (P=0.74).  |
| <b>Watson, M. et al. (2010)</b> | To compare attitudes of hospice staff towards weight loss and weight assessment in the hospice setting with those of patients with advanced malignancy in the hospital outpatient setting.                 | Hospices (n=71 doctors, 74 nurses); Oncology outpatients (n=129) | Quantitative | Questionnaire | n/a | Weighting practices vary across hospices in UK (NI) and Ireland and patients attending the majority of hospices are hardly weighed. While there is reluctance on the part of many hospice staff to weigh patients, most patients with advanced malignancy in the hospital setting do not report weight measurement to be upsetting. |
| <b>THEME: SYMPTOMS (PAIN)</b>   |  |  |              |               |     |   |
| <b>Barry, H. et al. (2012)</b>  | To explore the knowledge, attitudes and beliefs that nursing home managers hold with regard to the assessment and management of pain in residents with dementia and to determine how these may be affected | Nursing home managers (n=95)                                     | Quantitative | Questionnaire | n/a | Nearly all respondents (96%) provided care to residents with dementia, yet only 60% of managers claimed to use pain treatment guidelines within their nursing home. Nursing home managers were uncertain about how to manage pain in residents with dementia, demonstrating   |

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|                                     | by the demographic characteristics of the respondents.  |                                       |              |             |  | similar concerns about the use of opioid analgesics to those reported in previous studies about pain in older people. Managers who had received recent training were less likely to have concerns about the use of opioid analgesia than those who had not received training.   |
| <b>Rafferty, M.N. et al. (2012)</b> | To assess the economic cost of chronic pain in Ireland. | Individuals with chronic pain (n=140) | Quantitative | Assessments | Chronic Pain Grade Questionnaire (CPG); Client Services Receipt Inventory (CSRI) | Mean cost per chronic pain patient calculated per year across all grades of pain, with mean costs increasing according to the severity of pain. Those with clinically elevated depression scores had costs that were twice as high as people who scored below the depression cut-off score. Chronic pain services in Ireland are generally under resourced. Improved coordination and better management of patients via interdisciplinary pain rehabilitation program is essential. |

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| <b>Alaouabda, N. et al. (2011)</b> | To describe the pattern of chronic pain practice (CPP) among consultant anaesthetists in Ireland.   | Consultant anaesthetists (n=127) | Quantitative                 | Questionnaire                                | n/a | While 28% of responding anaesthetists were involved in CPP, in the majority of cases, this accounted for less than 20% of their clinical time. 39% of those involved in CPP had previous training in chronic pain management. The types of CPP included nerve blocks (67%) and pharmacological treatment (44%) in non-cancer pain (67%) and cancer pain (61%) patients. Epidural steroid injection was the most commonly practiced intervention (89%). |
| <b>Brown et al. (2011)</b>         | To develop the nursing practice context to enable more effective pain management with older people. | Nursing staff (n=48)             | Emancipatory Action Research | Focus groups; reflective sessions; workshops | n/a | 3 key themes (psychological safety, leadership, and oppression) and 4 subthemes (power, horizontal violence, distorted perceptions, and autonomy) were found to influence the way in which effective nursing practice was realised. Within the theme of 'context', effective leadership and the creation of a psychologically safe environment were key  |

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|                                   |   |   |                            |               |   | elements in the enhancement of nursing practice.   |
| <b>Cornally, N. et al. (2011)</b> | To explore the help-seeking behaviour, individual characteristics, attitudes, and beliefs of older adults with chronic pain in an Irish community setting.  | Older adults with chronic pain (n=72)   | Quantitative               | Questionnaire | Level of Expressed Need Questionnaire; Pain Attitudes Questionnaire; Pain Beliefs Questionnaire | Individual characteristics associated with help-seeking behaviour were female gender, increasing age, higher education, living alone, and severe pain. High levels of stoicism indicated that participants were more likely to believe they had superior pain control and courage in the face of pain and were not willing to disclose their pain to others. Participants had moderate age-related beliefs about the origin of pain. |
| <b>Rowley D. et al. (2011)</b>    | To identify this cohort of patients within our practice, to review the use of opioid analgesia in these patients, to identify the characteristics of this patient group, and to review the literature on the topic. | Patients (n=12) referred to the palliative care service with cancer pain who were on MMT. | Retrospective chart review | Chart review  | n/a   | This study demonstrated that significant difficulties were experienced in achieving pain control in this patient group. Although half of the patients were not on opioid analgesia on referral to palliative care, all required opioids to achieve pain control. Furthermore, multiple analgesic agents were required in 70% of patients.  |

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| <b>Duignan, M. et al. (2009)</b>  | To compare how barriers to pain management in emergency departments are perceived by nurses in the Republic of Ireland and in the United States.                                       | Hospital sites (n=5); Emergency nurses in the HSE area (n=81) | Quantitative               | Questionnaire | n/a | Most nurses in the study (n=67, 83 per cent) had undertaken no pain management training. Most barriers to pain management identified by the participants can be described as 'organisational'. The most frequently identified barrier in this study was the inability to give patients analgesia until medical diagnosis was made. Lack of time to assess and control pain adequately was identified by RoI nurses as the second largest barrier. Other challenges reported. |
| <b>THEME: SYMPTOMS (PHYSICAL)</b> |  |   |                            |               |     |  |
| <b>White, C. et al. (2009)</b>    | To determine which symptoms experienced by patients admitted to a specialist palliative care unit are self-reported (SR) and which are only detected with systematic questioning (SQ). | Patients' charts (n=50)                                       | Retrospective chart review | Case review   | n/a | The most common SR symptoms were pain, bowel disturbance, nausea or vomiting, mobility problems & loss of appetite. The most common SQ symptoms were weight loss, fatigue, loss of appetite, mobility problems, edema/ lymphedema, oral symptoms, confusion/   |

memory loss, sleep problems, bowel disturbance, drowsiness, and low mood.

# THEME: SYMPTOMS (PSYCHOLOGICAL)

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| <b>Anderson, T. et al. (2008)</b> | To assess whether the use of CBT techniques in hospice patients is an acceptable intervention.              | Patients (n=11); in-patients & day hospice                             | Mixed methods | Assessment; semi-structured interviews | Hospital Anxiety and Depression Scale (HADS) | This study showed that a palliative care professional with short training in CBT was usefully able to apply CBT techniques to hospice patients with mild-to-moderate anxiety or depression. |
| <b>Sharp, L. et al. (2012)</b>    | To investigate associations between cancer-related financial stress and strain and psychological well-being | Individuals post-diagnosis with breast, prostate & lung cancer (n=654) | Quantitative  | Questionnaire                          | n/a  | Cancer-related financial stress and strain were consistently associated with increased risk of adverse psychological outcomes (depression, anxiety and distress).                           |