



Spring/Summer 2015

Palliative and end of life care

‘Priority Setting Partnership - putting patients, carers and clinicians at the heart of palliative and end of life care’

Marie Curie and the James Lind Alliance

Liz Reed

Research Lead,
Princess Alice Hospice

Palliative and end of life care is an under researched area of care. In response to this, Marie Curie and the James Lind Alliance developed a partnership in 2013 to direct future research funding to research areas identified as important to patients and their families.

This initiative aimed to give patients, current and bereaved carers and clinicians an opportunity to contribute to research in setting priorities in palliative and end of life care. Through a wide consultation with these groups, a survey was disseminated by stakeholders via email, newsletters, social media, websites, presentations and conferences. It is reassuring to us that Princess Alice Hospice’s organisational strategy and research development mirrors some of the outcomes of this initiative.

From the 1403 responses received and through a consultation and a steering group the top 10 unanswered research questions were identified.

The TOP TEN unanswered questions in palliative and end of life care are:

1. What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice?
2. How can access to palliative care services be improved for everyone regardless of where they are in the UK?
3. What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients preferences?
4. What information and training do carers and families need to provide best care for their loved one who is dying, including training for giving medication?
5. How can it be ensured that staff, including healthcare assistants, are adequately trained to deliver palliative care no matter where the care is being delivered?
6. What are the best ways to determine a person’s palliative care needs and initiate and deliver this care for patients with non– cancer diseases?
7. What are the core palliative care services that should be provided no matter what the patients’ diagnoses are?
8. What are the benefits, and best ways, of providing care in the patients home and how can home care be maintained as long as possible? Does good coordination of services affect this?
9. What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff they have contact with and does this improve quality of care? Would having a designated case coordinator improve this process?
10. What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties?

This initiative allows grant funders, researchers and clinicians to target these areas of care. To see the whole report visit: www.palliativecarepsp.org.uk/finalreport

User involvement in palliative care research

In recent years the involvement of service users in healthcare research has been increasingly encouraged with innovative examples of service users prioritising, designing, undertaking and disseminating research^{1,2,3}.

While user involvement in palliative care can be challenging the involvement of patients and families in a focused way can add significant value, let alone a pragmatic voice to the research process.

The National Institute for Health Research identifies five principal stages of research where user involvement should be considered in research:

- The development of the grant application
- The design and management of the research
- The undertaking of the research
- The analysis of the research data
- The dissemination of research findings

(NIHR, 2010)⁴

Princess Alice Hospice is using a model of user involvement which is determined by the focus of each research study. For example, we are currently designing a study exploring the last 12 months of life for dementia patients. A member of this study steering group is Rosemary Copsey, the wife of a man who died with dementia (see below). This meaningful and focused engagement has and will continue to influence our project development. For example, ensuring questionnaires are written sensitively and are understandable and accessible to the population we serve.

This is a pragmatic approach within a population who's physical and emotional wellbeing can fluctuate. So focused involvement for each research project is valuable but not too arduous for patient and families.

References

1. Wright, D. Corner, J. Hopkinson, J. Foster, C. The case of user involvement in research: the research priorities of cancer patients. *Breast Cancer Research* 2007,9(suppl2):S3

2. Hepworth, C, Wray, J and Scanlon, K 2012, User involvement in research: A case study of breast cancer care's Service User Research Partnership , in: *INVOLVE - Involving NHS service users in research*, 13-14 Nov 2012, Nottingham

3. Scanlon, K. Reed, E. Wray, J. Fenlon, D. Moving Forward Developing an information resource for breast cancer patients at the end of hospital based treatment. *BMJ Support Palliative Care* 2011;1:A10

4. National Institute of Health Research. Patient and public involvement in health and social care research: *A handbook for researchers*. 2014. NIHR

My husband Lesley (pictured) had Alzheimer's disease. The start was very insipid and the signs were there for four years before a diagnosis was made. Having a background in nursing I was able to work with him during the early stages, helping with all the maintenance jobs around the house as we were both retired. The early stages were reasonably smooth, moving house did disturb him a little.

The journey got more bumpy, as the disease progressed, he went to a day centre, which he thoroughly enjoyed, he was always cheerful and smiling, I was lucky he was never violent. I was able to keep him at home until the last six weeks when he went to a nursing home with two admissions to hospital during that time.

These experiences have given me a very keen interest in the care of people with dementia and the problems carers have to face on the journey. I have voluntary jobs with the Alzheimer's Society, which keeps me in contact with dementia sufferers and their carers. I can understand their difficulties and help with ideas and suggestions.

Being part of the Hospice dementia research steering group is very interesting and enables me to put forward my experiences. Hopefully the research will lead to a far greater understanding of the needs of the patient and the difficulties of the whole family, who have probably been mourning the loss of their loved one for sometime as the person they knew had been lost somewhere during the journey.

As the last months approach there needs to be a great support network for the family and in particular the carer, for the patient the confusion covers up all around them, so usually by now distress is not a problem for them.

User involvement: one relatives story.

Rosemary Copsey



Current research collaborations

Oasis Study: an observational study of the frequency of oral symptoms in patients with cancer.

Dr Andrew Davies,
Consultant in Palliative medicine,
Royal Surrey County Hospital.

LEGACY study

Peter Barry,
Consultant Oncoplastic Breast
Surgeon, Royal Marsden NHS
Foundation Trust.

Evaluation of Schwartz Rounds

Professor Jill Maben,
King's College, London

For more information on these studies please visit our website:

www.pah.org.uk/research-collaborations

17th Dementia National Conference, London

Charlotte Leach, Speciality Registrar, Princess Alice Hospice

I was fortunate to attend this two day conference held in February 2015. The theme of the conference was, "Dementia Across Health and Social Care", and included a range of speakers from the disciplines of Old Age Psychiatry, Neurology and the Care Quality Commission (CQC).

The conference opened with a keynote address by John Rouse, Director General of Social Care. This included an overview of the "Dementia 2012 report", which draws attention to the fact that 77% of patients with dementia feel anxious or depressed, and 67% do not feel part of a community. As such, there is a significant national drive for "Dementia Friendly Communities", which aims to actively involve people with dementia in community living; for example, providing clear and simple signage in public places.

David Behan, Chief Executive of the CQC, gave an excellent presentation on the inspection process of hospitals and care homes, including mention of a national CQC report entitled, "Cracks in the Pathway". This report concludes that care for people with dementia is of variable quality, but that most people with dementia will experience poor care at some point during their care pathway. The report also acknowledges that there are several aspects of excellent care across hospitals and care homes, and highlights the importance of individualised, person-centred care in an appropriate environment with specially trained staff.

From a clinical perspective, it was fascinating to learn about the new investigations currently being used for dementia diagnosis. Traditionally, CT scans are often used in the initial assessment phase to exclude other diseases, such as brain metastases. Technology is rapidly developing, and newer imaging techniques such as PET scans (a CT scan which assesses the brain's glucose or oxygen uptake) are becoming increasingly commonplace. The new imaging techniques aim to improve the rate of accurate diagnosis, and differentiate more clearly between the sub-types of dementia.

The conference also included several presentations on drug management of dementia, including a comprehensive overview of the harms of antipsychotics in dementia. Dr Roy Jones, Research Institute for the Care of Older People, highlighted the dearth of recent new drug treatments for dementia. The most dementia drug, Memantine, was produced in 2002, meaning that in comparison to cancer drugs, the rate of development of new dementia drugs lags behind significantly.

This conference provided a great opportunity to learn more about current practice in health and social care for dementia, and moreover, to improve knowledge and understanding in order to provide the best possible level of care for patients with dementia referred to Palliative Care services.

Making the difference at end of life: Evidence from chaplains' case study research

Study Day/Conference at Princess Alice Hospice
30 March 2015

Reverend/Dr Steve Nolan,
Chaplin at Princess Alice Hospice

Interest in spiritual care is growing among nurses and other healthcare professionals, but many say they feel under-prepared and ill-equipped to deliver spiritual care.

Chaplain case studies can give a helpful insight into spiritual care and the role of the chaplain. Very few case studies, however, have been published and those that have been are difficult to access. Our chaplain, Steve Nolan, with Professor George Fitchett from Rush University - Chicago, has edited a book-length collection of chaplains' case studies, *Spiritual Care in Practice* (Jessica Kingsley Press).

Together with Revd Dr Chris Swift, a contributor, they launched the book at a study day/conference hosted at the Hospice.

George Fitchett

Chris Swift

Steve Nolan

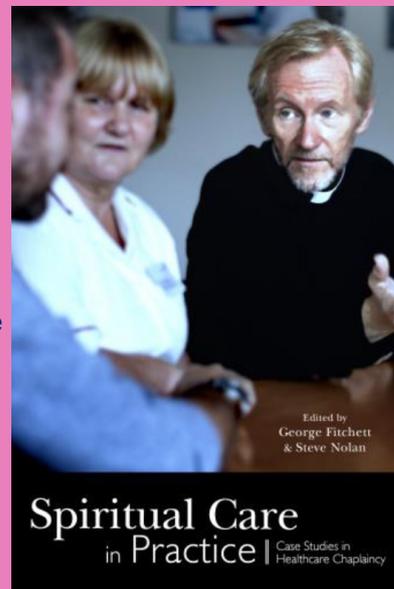


Prof Fitchett began the day outlining the value of case study research and presenting the case study model he developed that is used in the book. Chris Swift and Steve Nolan then presented their own cases, describing the spiritual care relationship with a focus on the chaplain's assessment and interventions. Both presentations were followed by small-group discussion and whole group feedback.

Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy

G Fitchett & S Nolan (eds)
(2015)

These diverse case studies make a strong case for the importance of effective spiritual care in healthcare and provide unprecedented insight into the essential role of the chaplain in the healthcare team.



Presented alongside critical reflections and responses from professionals within chaplaincy, psychology, psychiatry and nursing, they provide an honest and detailed look into how healthcare chaplains actually work with the people in their care and reveal the vital role of narrative and imagination in effective transformative practice.

From a 16-year-old with a belief that God would enable a miraculous recovery from paralysis, to an African man with a history of psychosis and depression whose cultural belief in witches complicated his treatment, to a dying Jewish man, aggressive and isolated due to his traumatic life experiences, each case includes insight into the patient's needs and chaplain's perspectives, discussion of spiritual assessments and spiritual care interventions, and accounts of significant encounters and dialogues.

The nine paediatric, psychiatric and palliative case studies and reflections in this ground-breaking book will enable chaplains to critically reflect on the spiritual care they provide and communicate their work more effectively, help healthcare professionals develop a clearer understanding of the care chaplains deliver, and provide an informed perspective for those who develop policy around spiritual care and need to make the case for chaplaincy services.