

2018 Hospice UK Conference Round Up

Liz Reed, Research Lead, Princess Alice Hospice

This year's Hospice UK conference was in a very wet and windy Telford. But that didn't stop palliative care professionals from around the UK travelling to hear and share the latest evidence and innovations in palliative care. The focus of the conference was '**Transforming Palliative Care**' and opening the conference was the first Plenary session by Heather Richardson and Shaun O'Leary from St Christopher's Hospice. Their talk was '*Re-invention—of course, but how do we do it?*' This fascinating yet challenging presentation began by identifying the drivers for change with the ageing population requiring health and social care and a health service under increasing strain to meet the demands when funding is limited and there is a shortage of people entering healthcare professions.

'Living well' with a life limiting illness has a different emphasis than it did 50 years ago and the complex problems associated with long term illness such as multi-morbidity, social isolation and financial burden as well as families and carers potentially facing the burden of care. Heather and Shaun challenged that current models of hospice care are already under strain and are not fit for the future. New initiatives such as retirement villages may provide the opportunity to integrate palliative care earlier and more naturally into the process of aging. Likewise in the future Care Homes will be the most common place to die so partnerships, investment in care and education is essential to ensure people are well cared for at the end of their lives. This plenary was both challenging yet insightful, encouraging delegates to consider the future transformation of palliative care and be pro-active rather than reactive.

While Heather and Shaun lead the main stage, there were many small sessions that were really interesting and useful. Jed Jerwood, Clinical Academic Researcher and Art Therapist John Taylor Hospice in Birmingham ran a workshop encouraging research dissemination beyond academic journals called '*Thinking outside the box*' using social media as a medium for 'sound bites'.



He gave one example of an academic paper having 50 reads on Researchgate but 3000 reads on Twitter. So using different media such as Twitter, Infographics, podcasts or YouTube are cost effective and it means research findings reach a wider more diverse audience alongside the academic publication.

Another interesting session was by Dr Jamilla Hussain, NIHR Clinical Lecturer from the Wolfson Palliative Care Research Centre. The title of her talk was '*Why missing data matter—a guide for palliative care practitioners*'. Jamilla undertook a systematic review and meta-analysis of randomised controlled trials testing palliative interventions and found that palliative care trials have around 23% of their data missing and 62% do not achieve their minimum sample size. Those with poorer performance status were more likely to have missing data questioning the validity of palliative care research with significant data missing. Dr Hussain said this reduces the power and introduces potential bias and questions the generalisability of palliative care trials. Considering future research exploring trial burden and an assessment of bias should be routinely reported.

There were so many fantastic conference posters. To see the conference abstracts please go to: BMJ supportive and palliative care November 2018 volume 8 supplement 2.

To see the conference posters Princess Alice Hospice took to the conference please go to page 6.

Health and social care professionals' experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis.

Ms P Franklin¹ Dr Anne Arber,¹ Dr Liz Reed² and Professor Emma Ream¹. Pall Med, 2019, Vol. 33(1) 49–65

As part of a research partnership between Princess Alice Hospice and the University of Surrey, doctoral student Penny Franklin undertook this systematic review. Below is a summary of that review.

Background

If children are not prepared for the death of their parent, or supported afterwards, they are more likely than their peers to have higher levels of psychiatric needs and absence from school. Health and social care professionals are important in helping parents to prepare their children for their death and support their children, however, professionals struggle to do so. We wanted to understand what the experiences of health and social care professionals were when supporting parents with dependent children when a parent has a life limiting illness.

Design

A systematic qualitative review and synthesis of existing literature on the experiences of health and social care professionals from January 1996– July 2018.

Data sources

MEDLINE, CINAL, PsychINFO, PsychARTICLES and PROSPERO searched for qualitative studies reporting health and social care professionals' experience of supporting parents and children during ,and following, the death of a parent.

Results

The search yielded 15,758 articles of which 15 met the inclusion criteria. Thirteen included professionals' experience of supporting parents and children before death and two supporting the surviving parent and children in bereavement. A total of 312 health and social care professionals took part in the studies, the majority were nurses (n277).

Summary of findings

Three analytical themes were identified: 1) aspiring to deliver family -focussed care 2) health and social care professionals' behaviours and emotions 3) improving connections with parents and children.

1. *Aspiring to deliver family focussed care*

Health and social care professionals aspired to deliver family-focussed care, connecting with parents to help them prepare their children and supporting the surviving parent and children after the death. Facilitators to connecting were: developing an early rapport; sensitivity to parents wishes about how to support their children. Connecting directly with children was aided by a family friendly environment and education on communication with children. Barriers were the fear of 'making it worse' or 'saying the wrong thing' and perception of a lack of skills preventing engagement with children and families. Families blocking communication around death and dying making it hard for professionals to connect with children.

Parental death was reported to be veiled in a 'shroud of secrecy' and there was some evidence that families blocked communication with children about anticipating and adjusting to parental death.

2. *Health and social care professionals' behaviours and emotions*

Under this heading there are 4 sub-themes 1) Empathy and sympathy -connecting as a parent themselves 2) personal emotions and professional behaviours 3) distancing and detachment and 4) managing health and social care professionals' emotions through peer support.

3. *Improving connections with parents and their children*

Professionals sought affirmation from employers of their supportive role and to prevent children being overlooked when a parent is dying ,they wanted organisational policy. Nurses highlighted the need to formally identify children and wanted training in communicating with patients who are parents and with their children.

Conclusion

Health and social care professionals aspire to connect with parents and children. For this to happen they want support from their employers, education, and policy that recognises the importance of this work.

Developing a Faculty of Evaluation Champions

Jane Berg, Deputy Director Skills, Knowledge and Research, Princess Alice Hospice

Historically most of the evaluations undertaken at Princess Alice Hospice were done by the Research Lead. To increase capacity and expertise in evaluation throughout the Hospice a Faculty of Evaluation Champions was developed. Five members of staff from around the hospice came together to undertake a 12 month training in all aspects of evaluation with mentorship from Professor Ann Ooms, from the Faculty of Health, Social Care and Education, Kingston University and St George's, University of London.

Aim

To expand our capacity and expertise in conducting evaluations and to embed this in a variety of departments. The five participants and their projects they undertook are below.



Jana Jeyakumar Consultant in Palliative Medicine

The project aimed to identify Hospice@Home patients who would benefit from a medical review and to then look at the impact of the medical review. The findings aim to make the medical input to the Hospice@Home team more effective and efficient. The next step will be to validate the tool that was developed.



Vanessa Hill Volunteering Lead

Based on an established model, a discharge buddy volunteer programme was created to support patients and families on discharge from the Hospice in-patient unit. The volunteer training and the role was evaluated assessing the discharge buddies' learning and development and their experience of the discharge buddy role.



Konstantina Chatziargyriou Quality Improvement Manager

The binary purpose of this project has been to evaluate the process of introducing and adopting the Integrated Palliative Care Outcome Scale (IPOS) at Princess Alice Hospice, In-patient Unit (IPU) as well as to explore and identify perceptions of the IPU staff around effectiveness of the measure and its utility in clinical practice.



Angie Redpath Nurse Consultant

The purpose of the evaluation was to explore the impact of The Enhanced Support Service (hands-on care) on the wider hospice@home team ensuring resource and skill are allocated for the number of patients supported as well as consideration given to how to reach more people.



Liz Reed Research Lead

By evaluating the whole Evaluation Champion project we aimed to explore the personal development of the Evaluation Champions, identify enablers and barriers to staff undertaking evaluation and determine the sustainability of a Faculty of Evaluation Champions.

Conclusion

Over the 12 months all the Evaluation Champions developed knowledge and skills in evaluation and will continue to be the resource on evaluation in their departments. They will continue to be mentored over the next year as their role develops. By developing staff evaluation skills in diverse departments throughout the organisation we are expanding our evaluation capacity and embedding the process of evaluation in everything we do going forward.

Case study publication: Decision making flowchart

Steve Nolan, Chaplain, Princess Alice Hospice

Clinicians are constantly dealing with and learning from challenging situations. Often, the learning is particular to the individual's professional practice and can be discussed in reflection practice or supervision. On other occasions, the learning could have wider application, in which case the situation could – perhaps should – be written up as a case study to aid professional development and thereby benefit future patient care.

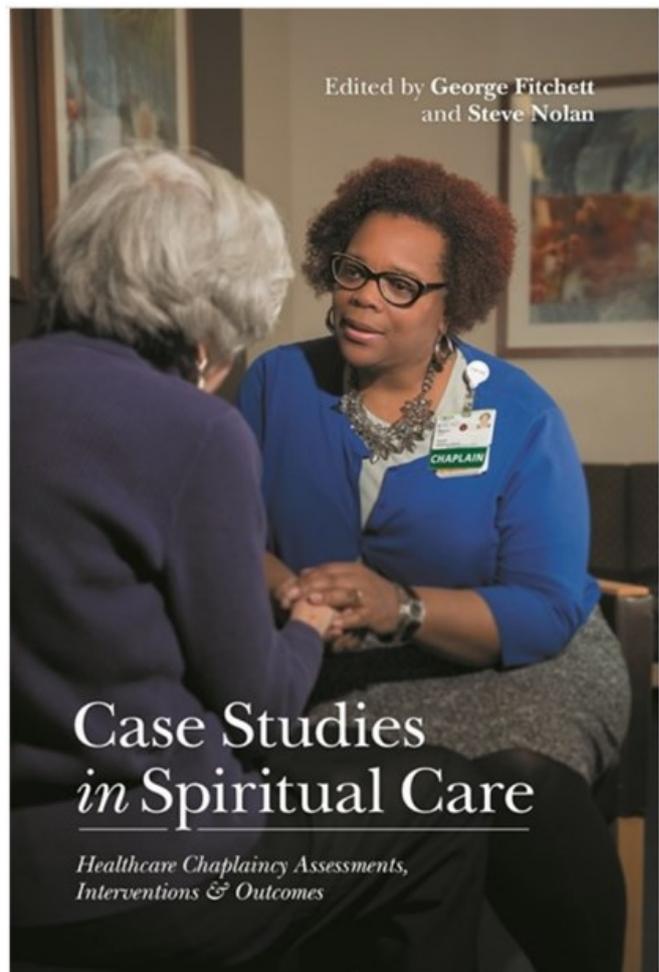
Any clinician wishing to write a case study faces an immediate question, which concerns their right to publish material that is personal to another individual. This question has exercised a number of chaplains who have been contributing to the collection and publication of healthcare chaplains' case studies. Until recently, healthcare chaplains have lacked a body of case studies that might help to direct the profession. George Fitchett, of Rush University Medical Center, Chicago, first identified this lack in 2010 and began working with chaplain colleagues to rectify the situation (Fitchett and Nolan 2015, 2018). Since 2012, I have been working with Prof Fitchett to develop the project. The ethical question about publication was identified and addressed very early, but despite publications by ethicist Dave McCurdy aimed directly at the issue of publication, it continues to trouble chaplain-researchers.

I developed the healthcare chaplains' case study algorithm primarily as a tool to aid healthcare chaplains navigate the questions that will help them decide whether publishing a case study about their work with a patient would be ethical (see page 5). Clearly, patient confidentiality is of primary importance, and a chaplain-researcher will want to make every effort to gain informed consent from the patient concerned. This is the 'gold-standard'. However, this is not always possible, where, for example, the patient has died or has become untraceable, and there may be situations where it would not be desirable, for example, where the chaplain-researcher's raising the possibility of writing a case study would significantly alter the relationship of

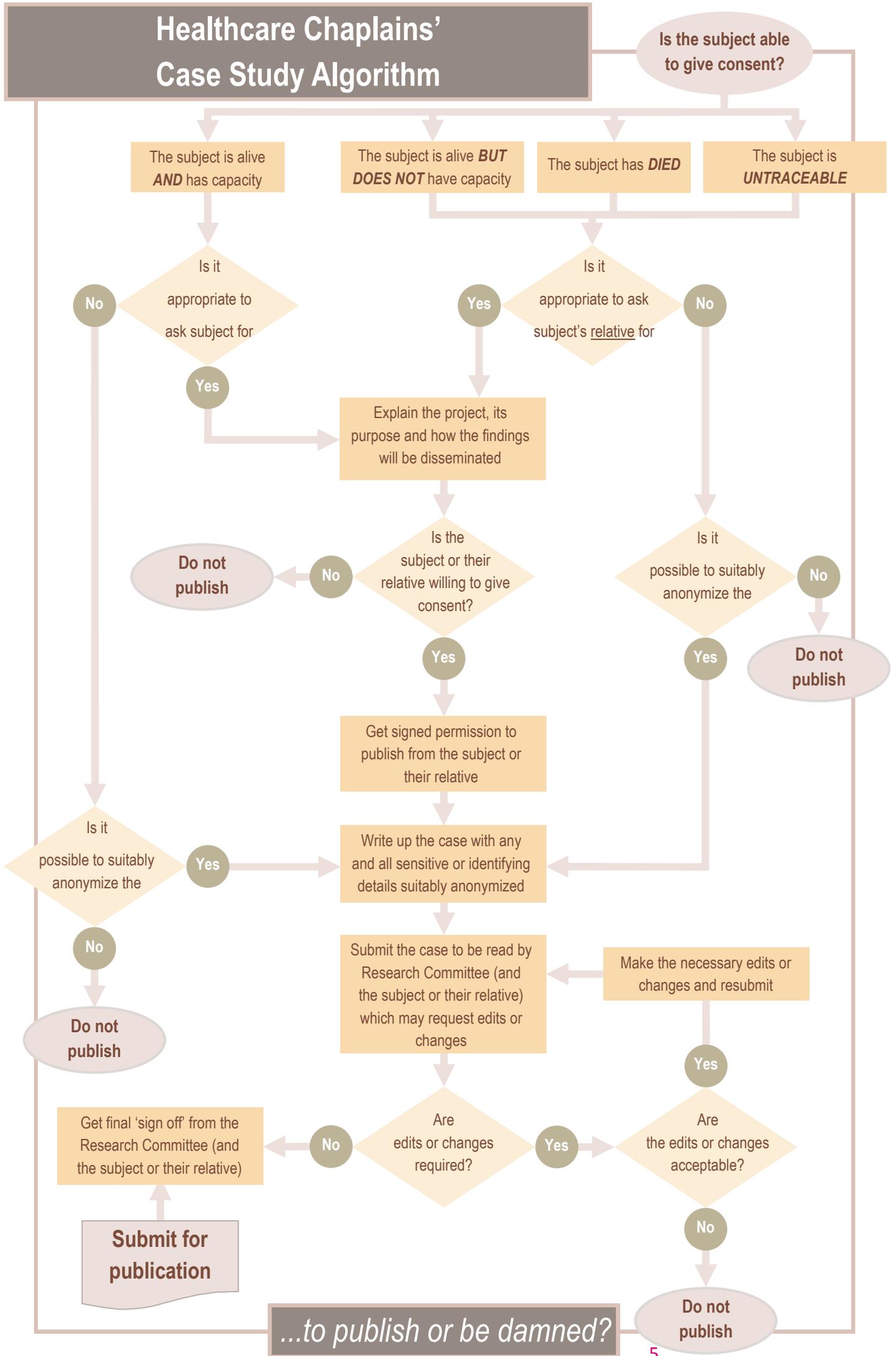
trust between the chaplain and the patient. The inability to publish cases due to a lack of consent would seriously impede the development of a profession that remains under-researched; so the algorithm takes chaplain-researchers through the issues they need to consider stage-by-stage towards the possibility of publication, including building in safeguards such as peer-review by professional colleagues.

Fitchett, G. and Nolan, S. (eds.) (2015). *Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy*, London: Jessica Kingsley.

Fitchett, G. and Nolan, S. (eds.) (2018). *Case Studies in Spiritual Care: Healthcare Chaplaincy Assessments, Interventions and Outcomes*, London: Jessica Kingsley.



Healthcare Chaplains' Case Study Algorithm



Princess Alice Hospice publications Autumn/Winter 2018

Journals

Franklin, P. Arber, A. Reed, L. Ream, E. Health and social care professionals' experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis. *Palliative Medicine*, 2018, Vol. 33(1) 49–65

Conference posters

2018 Hospice UK conference posters presented by Princess Alice Hospice

1. Clinical Supervision: is it fit for practice in 2018? [LINK](#)
2. Exploring the experience of personal bereavement for nurses working in a palliative care setting and the experience of returning to work [LINK](#)
3. Growing our evaluation expertise [LINK](#)
4. Reducing barriers to volunteering [LINK](#)
5. Using the Charityworks graduate scheme as part of a talent management strategy [LINK](#)
6. To publish or be damned: decision-making around patient confidentiality in case study research [LINK](#)
7. Bereavement Café: more with less in bereavement support [LINK](#)

Tackling poverty in Palliative Care 2018 conference poster presentation

Intimacy: the last taboo [LINK](#)

Current research projects

OPEL: Optimum Hospice at Home Services for End of Life Care

Claire Butler, University of Kent

What services influence the care of people with dementia in the last year of life?

Dr Jennifer Todd, Princess Alice Hospice

Development of an educative intervention for nurses working in palliative care to enhance their confidence and competence in communicating with parents and children when a parent nears end of life. Professor Emma Ream (doctoral study of Penny Franklin), a partnership between University of Surrey and Princess Alice Hospice

LEGACY (Rapid Medical Donation Programme for Breast Cancer)

Peter Barry, Royal Marsden Hospital

The influence of Intercultural Communication in discussion of Advance Care Planning: The case of nurses and care home residents in the UK

Jane Berg (doctoral study), Deputy Director, Skills, Knowledge and Research Princess Alice Hospice