

Exploring the experience of personal bereavement for nurses

working in a UK palliative care setting and the experience of returning to work .

A collaboration of 4 hospices in Surrey/Sussex

Background: Palliative care professionals are constantly exposed to death and dying and witnessing the distress this can cause both patients and families (Ablett et al, 2007). When experiencing a personal bereavement, the ability for nurses to work with patients who are dying can be challenging, affecting their personal and professional life as well as their psychological wellbeing, having an impact on their ability to work in an environment that reminds them of their dying relative (Marcella-Brienza and Mennillo, 2015). The personal grief response of professionals working in end of life care can remain hidden, as there is often an expectation that they should be resilient (Liben et al, 2008).

Methods: A multi-centre qualitative study involving four hospices. Inclusion criteria were nurses working in a clinical area who experienced a significant bereavement within the last 24 months. Advertisements were posted in clinical areas and snowballing was used to try and access nurses who had left the palliative care setting. Using purposeful sampling, we sought to recruit palliative care nurses across a range of age, role, gender, time in role, and time since bereavement.

A semi-structured interview approach was used.

Results: Four key themes emerged: circumstances surrounding the bereavement; conflict between the

personal and professional; returning to work and sources of support and grief as a continuum. Advice from participants to nurses who experience a bereavement in the future can be seen in Table 1.

Conclusions: Bereaved palliative care nurses strive to maintain their roles in the face of bereavement. Colleagues and managers have a significant part to play in supporting bereaved nurses but, as each person may adjust and cope differently, flexibility is essential and support should be offered beyond statutory leave.

Next steps: As a collaborative, we aim to develop an intervention working with our HR departments to support all healthcare professionals working in palliative care and evaluate this as a part of the process.

References: Ablett, J.R. Jones, R.S.P. (2007) Resilience and well-being in palliative care staff: a qualitative study of hospice nurses' experience of work. *Psycho-Oncology*, 16(8): 733-740

Marcella-Brienza, S. Mennillo, T. (2015) Back to work: Manager Support of Nurses Chronic Sorrow. *Creative Nursing*, 21(4): 206-210

Liben, S. Papadotou, D. Wolfe, J. (2008) Paediatric palliative care: challenges and emerging ideas. *Lancet*;371 (9615):852-64.

Table 1: Advice to bereaved nurses

Be open and honest with your team *'you spend the majority of your day with them'*.

Some bereaved nurses find working with supportive colleagues helpful *'something of the familiarity of work is very grounding'*.

Allow yourself to *'Take time out'* - before, immediately after, or at a later date.

'it doesn't [bereavement] stop when you come back to work'. It is important to understand the overlap between your personal experience and your professional role.

'Do what feels right for you' but be aware that may change.

Prevalence, symptom burden, and natural history of deep vein thrombosis in people with advanced cancer in specialist palliative care units (HIDDEN): a prospective longitudinal observational study.

Clare White, Simon Noble, Max Watson, Flavia Swan, Victoria Allgar, Eoin Napier, Annamarie Nelson, Jennifer Doherty, Bernadette Lee, Miriam J Johnson.

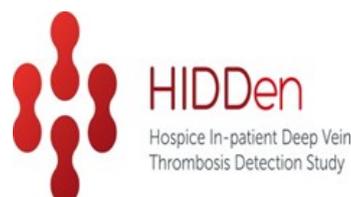
Lancet Haematology 2019;6:e79-88

Princess Alice Hospice took part in the HIDDEN study along side 4 other hospices. The aim of the study was to determine prevalence and predictors of femoral deep vein thrombosis in patients admitted to specialist palliative care units (SPCU).

Background: People with cancer have been found to have an increased risk of developing a venous thromboembolism, however, people with advanced cancer and a life expectancy of less than 3 months have been excluded from these studies. When people with cancer are admitted to hospital they will receive thromboprophylaxis routinely but the use of thromboprophylaxis in specialist palliative care units is not routine and is subject to debate. So thromboprophylaxis for people with advanced cancer is determined by place of care rather than clinical risk.

Methods: A prospective, multicentre, longitudinal, observational study in 5 specialist palliative care unit (SPCU). Eligible patients were over 18 years, admitted to one of the 5 SPCU, able to give consent or in the absence of capacity, consent was through a consultee, and estimated to have a prognosis of more than 5 days. They were screened within 48 hours of admission. data collected was: demographics, clinical characteristics, venous thromboembolism history, Wells score and blood test available from routine care. Outcome measures at baseline were bedside femoral and popliteal vein assessment by ultrasound, Australian-modified Karnofsky performance status (AKPS), clinical examination for signs or symptoms of venous thromboembolism, bleeding and medication record including anticoagulants. All measures were repeated weekly and medication changes recorded.

Results: Between June 20 2016 and October 16 2017, 1390 patients were screened of whom 343 were



recruited to the study. Of the 273 patients with evaluable scans, 92 (34%) had femoral deep vein thrombosis (DVT). Four participants with a scan showing no DVT on admission developed a DVT on repeat scanning over 21 days. Previous venous thromboembolism, being bed bound in the past 12 weeks and lower limb oedema independently predicted DVT. The presence of DVT on admission was not related to survival. Serum albumin, thromboprophylaxis and survival were not related to DVT.

Discussion: Approximately a third of cancer patients admitted to a SPCU had a femoral DVT. DVT is not associated with thromboprophylaxis, survival or symptoms other than leg oedema suggesting that the findings are consistent with venous thromboembolism being a manifestation of advanced cancer rather than the cause of death. Thromboprophylaxis appears to be of little benefit to cancer patients in a SPCU with poor performance status.

Dr Clare White, the study Co-Chief Investigator from Northern Ireland Hospice, Belfast, said:

"Patients approaching the end of their lives deserve the best care that can be provided, as often there is no second chance to get it right. This study should improve patient care through preventing patients like those in our study receiving clot prevention injections that are associated with minimal benefit and which might cause them harm."

Key messages from the Association of Palliative Medicine conference 2019

Craig Gannon, Medical Director, Princess Alice Hospice



Association for
Palliative Medicine
Of Great Britain and Ireland

One of the benefits of my two tenures on the APM Ethics Committee has been the opportunity to attend the APM's national conference, albeit with a need to contribute. This years 2-day conference was in Harrogate, which appeared a visit-worthy Yorkshire town (well, the bit between the railway station and my B+B!) even if very hilly (be warned if you plan a mid-conference run, wasn't easy!).

This like any conference offered genuinely new knowledge, re-hashed old knowledge and provided numerous, even if fleeting, opportunities to network (it was great to be able to grab 10 minutes with the likes of Dr Fliss Murtagh and Baroness Ilora Finlay to hear their perspectives first-hand / off the record).

The most interesting presentation for me was by Professor Irene Tracey, Head of Neuroscience at the University of Oxford, called '**How the brain perceives and modulates pain: lessons from advanced neuroimaging for the busy clinician**', which confirmed how functional MRI can show: (i) if analgesics are effective better than any trial (quicker, smaller numbers, more objective), (ii) that placebo-controlled trials mislead (good analgesics may have been inappropriately discounted) hence placebo-controlled trials cannot now be seen as the 'gold standard' anymore and (iii) that specific pathways are triggered by placebo, impacting on the experience of pain, necessitating a more positive re-framing of placebo-pathways as a potent target for relief. Of note, MRI has shown that a number, around 20% of people, have discomfort driven by non-pain pathways (where traditional analgesic

won't help) thus requiring attention to the 'comorbidities' of pain instead – in my mind, this equalled MRI scan evidence of pathways that explain refractory 'total pain', amazing, though inexplicably this was not flagged by the presenter, possibly as more to it, though she did describe 'bad cop' pathways in the brain that drive pain, in contrast to patients who don't get 'pain'/respond to analgesics, where different 'cop' pathways promote relief instead.

The star attraction was Angela Rippon, who kicked off the main conference as an advocate for better care for people with dementia. She was eloquent, intelligent and impassioned in her support for common-sense measures across all walks of life, in order for society to be more inclusive and supportive of people with dementia. Her honesty and insight, as she described her own experiences as a family member caring for someone with dementia were particularly powerful. Though many of us in healthcare would recognise and be quick to empathise, the unacceptable reality is that so many family members/society at large are under-prepared and under-supported to cope when their relatives have advancing dementia. Moreover, she had made impressive inroads by mobilising her social networks/big business in a way only celebrities can.

Unfortunately, as my time as an officer of the APM is over, I cannot legitimately justify attending next year's conference in 2020. While this means less work beforehand and less work while there, less performance anxiety, less time away from home, less disappointment at not sleeping that one night I should get an undisturbed night, less time stood up on an over-booked 3-hour train journey, less awkward chit-chat with people whose name I should remember but don't, while desperately balancing a plate of food, an orange juice and my conference programme etc, yet, strangely I will be really sad not to be there!

Introducing the a new role NIHR Palliative Care Research facilitator for the Kent, Surrey Sussex Network

Hannah Taylor, NIHR Palliative Care Research Facilitator for Kent, Surrey and Sussex



I am Hannah Taylor, the new Palliative Care Research Facilitator for Kent, Surrey and Sussex. I work for the NIHR but am based at St Catherine's Hospice in Crawley. My role is to provide research support and guidance for all seventeen hospices across the region. Access to this support will be via a research hub in providing resources relating to governance issues, policies and procedures, education, training and mentorship. This hub will facilitate the sharing of knowledge and encourage collaboration, assisting hospices, whether naive or experienced, to develop their research practice.

Both the hub and the role of the Palliative Care Research Facilitator are a direct action from the NIHR-CRN KSS palliative care research strategy 2018, with the vision of creating a model of hospice research that is both sustainable and cost effective and puts patients first. The strategy has key objectives set out over a three year plan.

Year One:

- Confirm current research status of hospices across KSS- complete
- Create research hub- ongoing
- Secure funding for facilitator post- complete
- Share governance procedures and policies- ongoing
- Support research naive hospices- visit already completed or booked at St Barnabas, St Wilfred's and Woking and Sam Beare.

Year Two:

- Demonstrate and promote KSS hospices as recruiting sites for studies.
- Promote of the benefits of hospice research and success.
- Encourage CIs to consider KSS as a good area for study recruitment.
- Encourage and support local teams to apply for funding.
- To consider the prospect and the technicalities of hospice carrying out commercial studies.

Year three:

- Supporting and generating KSS Principal Investigators.
- Attracting funding for KSS hospice studies.
- All research active hospices working to high standard of governance.
- Clear sharing of resources.
- A hospice leading on a research project.

The above is not the complete list of objectives. The strategy's implementation has commenced. Whether it is support a hospice by providing resources to set up journal club, recruiting to research, generating or leading research, our aim is to assist hospices in participating in research at their highest level.

I am available to ask any questions or any resources about research my details are as follows:

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'Do We Have a Case?' – Report on an International Conference on Case Studies Research in Chaplaincy Care, Amsterdam 5-27 February, 2019

Steve Nolan, Chaplain, Princess Alice Hospice

This two-day international conference on chaplains' case study research aimed to both summarise where chaplains' case study research has got to and act as a springboard to move the work on to the next stage. Held at the University Center for Chaplaincy Studies in Amsterdam, as a joint initiative between the Protestant Theological University, Amsterdam, and Tilburg School of Theology, the conference brought together around 80 chaplain-researchers and academics from the Netherlands, Denmark, Germany, the United Kingdom and the United States.

Plenary sessions on the first day were presented by Jacques Körver, George Fitchett and me. Dr Körver, a co-made an assessment of the DCSP collaboration that is working with around 60 chaplains and academics within the Netherlands, aiming to publish case studies from across the chaplaincy disciplines (healthcare, education, military). Prof Fitchett drew on his long experience in health research to review the history of chaplaincy research and to point a direction for future development. My presentation offered a first look at findings from the cases that have so far been published and the afternoon panel session gave chaplain-researchers the opportunity to share and discuss their work.

On the second day, for me the standout presentation was by Jan Willem Veerman, from Radboud University, Nijmegen. As a non-chaplain, qualitative researcher, the value of the work undertaken Prof Veerman and his colleagues has – like that of so many qualitative researchers – faced the challenge presented by the dominance of the randomised control trial (RCT) and the hierarchy of evidence paradigm.



In response, Professor Veerman and team have developed what they term 'the effect ladder'. Without disputing RCTs as the 'gold standard' for supplying evidence on the effectiveness of an intervention, Veerman argues that, because they are difficult to conduct, RCTs are in fact rarely performed in research into youth care practice, an area of interest for Professor Veerman. As a result, few interventions are able to claim a robust evidence-base (the situation is true for chaplaincy research). To address this, Veerman and team developed a staged model that allows researchers to develop effective interventions as they are carried out in actual practice.

Veerman's work in children's and youth care has strong parallels with chaplaincy and the effect ladder offers a way to use a research methodology appropriate to an intervention's stage of developmental. This approach is less intimidated by hierarchies of evidence and suited to the practice-based evidence that can be gathered in smaller-scale research projects.

Links from all the conference presentations and a paper by Veerman and van Yperen, giving a full account of the effect ladder, are available at: <https://ucgv.nl/>

A Goodbye

Liz Reed, our Research Lead leaves the hospice after 6 years. Led by Liz, we undertook a research strategy in 2013 and have since focused predominantly on non-malignant disease (dementia) and young families. We have hugely benefited from the partnerships Liz has forged with Professor Emma Ream at the University of Surrey and Professor Ann Ooms at the Kingston University and St George's, University of London amongst others. Over the 6 years, we have recruited to eight external research studies and three internal research studies. In addition, many staff undertaking MSc's were supported by Liz with the research element of their degrees. In total we recruited over 500 people to research. Liz is off to live by the sea but before she left she said '*I have loved working at Princess Alice Hospice. After over 40 years as a nurse and researcher, 25 of those being in palliative care, I think I saved the best until last. I have so enjoyed the role, the people and the place. However, its now time for some travel and a move to the Dorset coast!*'



Conference posters

Association of Palliative Medicine conference

Craig Cannon: Palliative Care and the Lack of Double Effect [LINK](#)

Jenny Palfrey (Darzi Fellow): Making the Unbearable, Bearable: A project to explore the potential use of digital technology to aid hospice care; focussing on remote consulting [LINK](#)

Current research projects

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

Jenifer Todd, Consultant in Palliative Medicine, Princess Alice Hospice

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

Dr Claire Butler, University of Kent

Developing Understanding of how the personal and professional background of the nurse from overseas influences end of life care in the care home setting in the UK

Jane Berg, Princess Alice Hospice

Exploring the experience of personal bereavement for nurses working in a palliative care setting and the experience of returning to work

Jennifer Todd, Princess Alice Hospice

Connecting with parents, and their dependent children before, and after, the death of a parent.

Penny Franklin, Doctoral student, University of Surrey