

Multi-Disciplinary meetings to ensure that the patient & their world are kept the centre of our focus.

P147 THE SOCIAL UNIVERSE - GETTING BEYOND GENOGRAMS TO MAP PATIENT NETWORKS

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Context Forecasts of profound demographic change and diminishing health care resources together with patient preferences to be cared for at home, suggest that future community support will need to be shaped very differently, identifying new sources of resilience.

Networks around people could be harnessed to offer social and practical support, and in many cases healthcare support. This underpins the public health approach to palliative care.

Proposal There is a presumption by practitioners that the traditional genogram describes the support network – this may be the case but it seems important to understand a more inclusive and interactive network, the strength and weakness of the links, potential for change and the conversations needed to facilitate strengthening of these links. Network ‘poor’ patients will also be identified.

The Social Universe Tool (based on Macy’s support map)

The palliative patient is given a blank sheet with their name in the centre and is asked to map all those people in their ‘universe’.

These may include :

- Relatives, friends and neighbours
- Facebook friends
- Work colleagues
- Members of groups or clubs

The thickness of arrows drawn in both directions between the patient and each name determines the strength of support given and received.

Reflections on conversations that need to happen to strengthen key relationships are formulated together

For example – there may be a thin line from a friend towards the patient – the patient feels this friend would like to help more – what conversation needs to happen to strengthen the universe ?

Initial results The Social Universe map has been piloted to look at acceptability and usability with 20 patients of different ages and backgrounds.

All patients have found it a creative and relevant way to understand their networks and to think about tactics to strengthen relationships !

Next Steps Formal evaluation with professionals and patients, followed by training of hospice practitioners to launch as part of routine holistic assessment.

P148 MIRRORING FAMILY IDENTITY THROUGH DOCUMENTARY FILMMAKING: INNOVATIVE WAYS OF WORKING WITH FAMILIES IN A HOSPICE SETTING.

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Background Expressive arts are increasingly being used within Palliative Care (PC) to add to desired outcomes. We wished to

develop these techniques working with families in a hospice setting.

Aims To explore & evaluate the use of documentary film making techniques in PC to support families and patients.

Method A film artist, resident in a hospice for a year, worked with staff, patients & families using & teaching camera & editing skills to produce documentary films. They took part in a series of qualitative interviews to explore their experience. 30 interviews were completed, transcribed verbatim & entered into Nvivo 7 for thematic analysis.

Results 12 families made films in an iterative process that included reflective listening & screening, which this paper will analyse as ‘mirroring’. These films had various purposes such as ‘legacies’, made for those facing bereavement, ‘portraits’ allowing the family to see & take stock of their life stories; ‘play spaces’, where family members could express the parts of themselves that may get submerged in the problem-solving ethos of dealing with illness.

Conclusion The families found making a documentary film about their life brought them together, allowing them to ‘tell their story’ & leave a legacy of family archive. Patients reported they enjoyed specifically seeing the closeness between the family members & the positive functioning of the family reflected in the film. The legacy aspect of the film is of particular importance to patients with young children. Documentary film goes further than the traditional ‘memory box’, it captures the day-to-day life of the family together reflecting the relationship the patient has with his/her family as well as mirroring the family identity. Working with a film artist in a hospice has equipped the staff with new technical knowledge & a ground-breaking documentary intervention to use with families in a PC setting.

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P149 DISCOURSE ON METHOD: TESTING A METHODOLOGY FOR USE IN UNDERSTANDING WHAT SPIRITUAL CARE SPECIALISTS MEAN BY ‘SPIRITUAL NEED’

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Aim To test a methodology for use in understanding what is meant by ‘spiritual need’

Background Nurses are required routinely to conduct spiritual assessments (NMC 2010). Yet, despite a growing literature around spiritual assessment (McSherry & Ross 2010; Holloway *et al* 2011), knowledge about what constitutes spiritual needs remains limited. Without this knowledge, nurses are ill-equipped to make their assessments (McSherry & Jamieson 2011). The methodology is intended to be used in a larger study aimed at building a spiritual need typology.

Method The pilot study – an interpretive study using a form of discourse analysis – worked with 9 spiritual care specialists, each of whom shared, in depth, one encounter with a person they considered had been in ‘spiritual need’. Working in focus groups and using semi-structured questions, the method aimed to:

1. gather narrative accounts about the experience of people in spiritual need;
2. generate descriptive vocabulary articulating those experiences.

Participants orally described their encounter, which they then documented on a specially designed form. Participants next

discussed their written accounts with colleagues to identify and record:

- *key words* that characterise the experience of spiritual need; and
- *indicators* (objective and subjective) of spiritual need.

Finally, participants wrote a brief, summary description of the spiritual need, which they further refined with their colleagues.

Result The pilot identified refinements to improve the methodology as an effective way of gathering data useful in building a typology of spiritual need.

Application to hospice practice With evidence growing that attending to spiritual needs has a beneficial effect on health outcomes (Koenig et al 2012), a clearer understanding of what constitutes 'spiritual need' is likely to have direct impact on patient care and health outcomes.

P150 DEATH ANXIETY RECOGNITION IN A PALLIATIVE CARE SETTING

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Death anxiety is the "feeling of dread, apprehension or solicitude (anxiety) when one thinks of the process of dying, or ceasing to 'be'." (1)

Introduction Recognition of death anxiety is important in hospice care, but assessment and management is often down to subjective interpretation and personal skills.

There are a number of formal death anxiety scales (2, 3) with an acceptable level of reliability, but these are not routinely used in hospice work. Informal assessment of death anxiety is based on narrative disclosure within a holistic assessment and covert death anxiety is often missed. (4). Generalised anxiety often masks the more specific concerns of 'death anxiety' – and the treatment may differ.

Death anxiety can be managed with psychological interventions specifically aimed at existential distress, spiritual support, and facilitation of open discussions regarding death. These include 'meaning-based' interventions and legacy work.

Standard health anxiety approaches within a cognitive behavioural approach (CBT) have been adapted to treat death anxiety with good effect (5); however a specific death anxiety model is not available.

As part of a Masters Degree in Cognitive Behavioural Therapy I plan to research and design a model of care for death anxiety that can be used in front-line palliative practice. The following work is a baseline survey to underpin the research.

Aim To establish current level of understanding, assessment and management of death anxiety at the Hospice of St Francis.

Method Inpatient staff completed an anonymous questionnaire to highlight :

- their understanding of the concept of death anxiety
- confidence staff feel in diagnosing and assessing death anxiety.
- subsequent management of death anxiety.

These questions consisted of rating scales and narrative responses.

Future work

- To develop an assessment tool to detect death anxiety in a hospice setting,
- To develop a CBT model specifically for the treatment of death anxiety.

P151 REAL TIME REPORTING PILOT IN END OF LIFE CARE

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Background It is acknowledged that to date, capturing meaningful and timely feedback from patients within the last year of life, and their families, remains a challenge.

Project aim and objectives The objectives of the project were to ascertain the acceptability and usefulness of a real time survey and reporting system to capture the experience of patients, families and carers receiving end of life care.

Organisations within Lincolnshire were invited to join the pilot and four different care settings, where end of life care is commonly provided were engaged; care home, persons own home, hospice and hospital.

Approach Survey questions were tailored to each care setting with volunteers and staff inviting participants to use a hand held 'ipad' device to feedback their experience of care; alternative options, such as web link and paper survey, were also offered.

Outcomes and application

- The pilot was successfully implemented across all four different care settings.
- The use of the devices and the length of the survey were acceptable to individual receiving care and their family member.
- The trial of a reworded 'family & friends' question with those at the end of life proved acceptable to the majority of users

The role of the volunteer was instrumental in engaging participants. Volunteers expressed satisfaction and reported back on the added value of one to one engagement with survey participants.

- Anecdotal feedback from the volunteers and staff suggested that patients and carers were happy to participate and expressed enjoyment in taking part. "Patients appreciate the opportunity to speak to someone and to have their voice heard as well as trying new technology"
- Provides timely, concise and meaningful information to service providers
- Provides opportunities for organisations to benchmark end of life care county-wide
- Next phase will seek to inform on further learning for a national roll out

P152 MAKING USER INVOLVEMENT HAPPEN

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Background Stakeholders need a voice that is focussed on the quality of a service rather than numbers. They want to provide feedback and make recommendations developing a true partnership. User involvement can provide this process. A group was set up 3 years ago to develop this and has now moved from "meeting" to "making happen"

Aim

- Help in identifying areas requiring improvement