

# People, Partnerships and Potential

## Oral Presentations

### Conference Papers 1

#### 0-1 DANCING FOR HEALTH – A PILOT PROJECT

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**Background** Coping with the physical and psychological changes associated with terminal illness can be extremely difficult, but being physically active can help people cope better with these challenges.

Partner dancing provides this by keeping the mind and body active and improving muscular strength, balance, coordination, cognitive function, social skills and self-confidence. It has the added benefit of allowing partners to participate, increasing patient quality of life and enabling them to enjoy being in the moment together.

The Dancing for Health project has been developed in partnership with a local dance school who have devised a specialised programme that recognises and takes into account the limitations of patients with terminal illnesses.

**Aim** To develop a specialised partner dancing programme that improves both the physical activity and wellbeing of terminally ill patients and their partners.

**Method** A tailored eight-week partner dancing programme is being delivered jointly by hospice allied health professionals and the dance school. Patients who would not ordinarily attend a public dance class have the opportunity to learn to dance with a partner - be that their own partner, family member or friend - in the hospice's safe and familiar environment, and engage in a fun activity that improves their physical, psychological and social wellbeing. **Results** It is hoped that the pilot will provide an evidence base to demonstrate the many benefits partner dancing can have on improving patients' health and general wellbeing, including improving self-confidence, self-esteem and cognition.

The programme will be evaluated using patient questionnaires including the Short Warwick-Edinburgh and Practice Research Network assessment tools.

**Conclusion** Terminally ill people have to make many adjustments to cope with the changes that illness brings. If successful, Dancing for Health could provide an opportunity to better support patients with managing physical and psychological adjustments, as well as enhancing their social wellbeing.

#### 0-2 DO SPIRITUAL BELIEFS INFLUENCE COPING MECHANISMS IN DEALING WITH DEATH AND DYING?

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This study aims to discover whether there may be a definable value in attempting to measure life purpose and spirituality as a means of coping with end-of-life issues. Does 'organised' religion and spirituality impact upon human beings' capacity to cope with ultimate life issues such as death and dying? In an endeavour to investigate a particularly challenging phenomenon, this study was

developed using the Grounded Theory approach. This approach was designed to develop important theoretical concepts from basic needs awareness. This study was designed as an attempt to peek behind the scenes of individual metaphysical and existential awareness. It provided a powerful opportunity to access notoriously inaccessible information from human consciousness. Applying a mixed method, each participant was given a questionnaire to complete, and a number of them were also interviewed. This provided the opportunity to expand upon a selection of responses to the questions presented.

Analysis of this study offers a unique insight into the personal thoughts and beliefs of individuals, faced with the expression of their intimate views on sensitive existential issues. The study has been developed using a non-partisan approach to spirituality and religion. Results, measuring a majority of 12 out of 14 participants, suggest that a variety of beliefs in spirituality and life purpose offer a form of existential acceptance and solace. This ground-breaking research focuses on not solely one religious or spiritual approach, but a significantly diverse range of views. The data highlight a new theoretical definition for human understanding, the Primary Existential Design (PED), which offers reasoning for individual perception of ultimate life and death issues. There is also compelling evidence of further understanding related to the phenomenological mystery of human consciousness.

#### 0-3 FACILITATING SUCCESSFUL IMPLEMENTATION OF A PERSON-CENTRED APPROACH TO CARER ASSESSMENT AND SUPPORT

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**Background** The Carer Support Needs Assessment Tool (CSNAT) intervention identifies and addresses family carer support needs towards end of life. This person-centred approach involves a change in practice from a practitioner – to carer-led assessment process. Numerous policies recommend carers' needs should be addressed yet there is little guidance on how to achieve this within palliative care. To address this gap and assist a change to a carer-led process, an implementation strategy for the CSNAT intervention was developed, of which facilitation is key.

**Aims** Investigate components of facilitation associated with successful implementation of the CSNAT intervention across a range of palliative/end-of-life care services.

**Methods** Qualitative: Interviews three and six months post-CSNAT implementation with 38 practitioners with the role of CSNAT 'champion' (internal facilitation) in 32 services. Researcher field notes collected from teleconference support sessions with 'champions' (external facilitation).

**Results** Successful implementation of the CSNAT intervention was associated with: utilising a teamwork approach to facilitation; the 'lead champion' having a leadership role in the service e.g. team manager; presenting a clear rationale why a change in practice was needed; reviewing progress and making changes to overcome identified barriers; 'champions' having good communication skills and authority to make changes. Larger services faced more barriers to facilitation e.g. difficulties with providing training to all staff and less frequent opportunities to review progress as a team. Aspects of context which constrained facilitation included the need to establish a new carer record, and organisational changes e.g. budget cuts, and a culture focused on the

patient. In contrast, support from management was one aspect of context which assisted with facilitation efforts.

**Conclusions** In addition to managerial support, establishing a team of practitioners to lead facilitation of the CSNAT intervention and regularly review implementation progress, is vital for implementation success.

This study was funded by Dimbleby Cancer Care.

## 0-4 ENABLING SUCCESSFUL HOSPITAL DISCHARGE TO HOME AT END-OF-LIFE: HOW CAN WE SUPPORT FAMILY CARERS?

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**Background** Successful hospital discharge and prevention of readmission often depend on carers' ability to support patients.

**Aim** To investigate how carers are supported during patient discharge from acute care towards end-of-life (EOL) and suitability of using the Carer Support Needs Assessment Tool (CSNAT) to improve carer support at discharge.

**Methods** Qualitative design: focus groups (FGs) with 40 practitioners supporting patient discharge from three English acute hospital trusts; interviews with 22 carers of patients discharged. 14 practitioners and five carers joined two final workshops. FGs/interviews/workshops explored current discharge processes and potential value of using CSNAT. Thematic framework analysis conducted.

**Results** Discharge processes were heavily focussed on patients' needs: there was no systematic approach to supporting carers. Practitioners and carers viewed CSNAT as highly relevant and could be used to facilitate much needed EOL conversations which often were absent and to manage carers' expectations of their caregiving role at EOL, including support available (or not) in the community. They also provided advice on feasibility of using the five stage CSNAT approach at discharge.

- Stage 1. CSNAT introduction was seen as crucial, to overcome carer reluctance for support for themselves and to avoid it being viewed as 'another leaflet'
- Stage 2. Carers' consideration of needs: useful to help manage expectations of caregiving, but carers need to be given time to reflect
- Stage 3. Assessment conversation: CSNAT questions seen as a useful trigger, but a separate space and a separate focus from patients needed.
- Stage 4. Action planning: an essential part of the process – giving out the CSNAT was not 'job done'
- Stage 5. Review: challenge in this context is the transition to home, but CSNAT as a carer-held record was a possible solution.

**Conclusion** CSNAT shows good potential to enhance carer support at hospital discharge and play a role in preventing readmissions towards EOL.

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## Conference Papers 2

### 0-5 COMMUNICATION ABOUT CARDIOPULMONARY RESUSCITATION DECISIONS AT A UK HOSPICE INPATIENT UNIT

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**Background** A 2014 court ruling in the UK established that the only justification for NOT discussing a "Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) order with a competent patient is either patient choice or potential "harm" to the patient (not distress).

**Aims** This study aimed to establish current practice in communication when making DNACPR decisions, the impact of the ruling and the interpretation of "harm".

**Methods** The records of 150 hospice inpatients admitted after the ruling were screened. An anonymous survey was sent to hospice doctors and hospice nurses trained to complete DNACPR orders.

**Results** DNACPR decisions were made without discussion with competent patients in 6/150 cases. Reasons documented included: patient choice, the decision was implied from previous discussions, the patient was too unwell. All six decisions were discussed with the family.

Survey response rate was 90% (28/31) with equal numbers of specialist nurses and doctors. 21/28 respondents made DNACPR decisions at least monthly, 6/28 had made these decisions without discussion with a competent patient in the past six months, 20/28 were aware of the ruling and 16/28 felt it would impact on their practice.

Examples of impact on practice included; increased awareness of need to keep up-to-date, forcing earlier DNACPR discussions, pressure to discuss decisions with all patients, increased likelihood of exploring patient choice, increased involvement of family. Interpretations of "harm" included: more than distress, physical harm to self/others, psychiatric disorder, damage to doctor-patient relationship, distress close to the end-of-life.

**Conclusions** Only a minority of decisions were not discussed with competent patients. Not all relevant health care professionals are aware of the recent court ruling. Of those who were, over half felt it would impact upon their communication practice. There is a need for clarification of what constitutes harm rather than distress.

### 0-6 DELIVERING INTEGRATED HOSPICE BASED CARE IN MOTOR NEURONE DISEASE

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**Background** 2016 NICE guidelines on assessment and management of Motor Neurone Disease (MND) recommend that patients should have access to multidisciplinary, integrated care with access to local services and support groups.