



FoNS Improvement Insights

Raising the Profile of Preferred Priorities at the End of Life with Patients at St Nicholas' Hospice

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Duration of project: April 2010 – April 2011

Keywords: End of life, hospice, advance care planning, experience based design, patient stories, patient preferred priorities of care

Project background

The need to raise End of Life Care (EoLC) issues in the UK and promote the wishes of individual service users is driven by several reports and government initiatives e.g. *the End of Life Care Strategy* and the *Gold Standards Framework (GSF)*. The GSF identifies three steps that encompasses identifying patients in their last year of life; assessing their clinical and personal needs; advance care planning (ACP) and developing an individualised action plan of care. ACP is a process of reflection on and communication of a person's preferences for future healthcare, to be used in the event that they become incapable of giving informed consent. The literature on EoLC suggests that current care provision does not match that desired by the public. The project team felt that the hospice movement should be at the forefront in achieving patient's wishes at the end of life.

Aim and objectives of the project

The aim of the project was to establish working practices that would ensure that every patient was able to express and plan their preferred priorities of care for end of life. To achieve this aim the objectives of the project were to:

- Establish current practice in identifying patient's preferred priorities of care for end of life
- Explore and understand the subject of preferred priorities of care for end of life from a staff and patient perspective
- Identify recommendations to improve EoLC practice

Key activities and outcomes from the project

A number of approaches were used to achieve the project objectives. These included, staff questionnaires, discussion during a staff education session and patient interviews. Current advance care planning at St Nicholas' Hospice includes specific documentation to outline EoLC priorities. A randomised audit of this documentation (n=20) demonstrated a significant shortfall in the recording of patient's preferred priorities for care at the end of life.

- Exploring the staff perspective

An anonymous questionnaire was designed and distributed to all doctors, registered nurses and nursing assistants on the hospice in-patient ward (n=56). It examined completion of the EoLC documentation with patients; values placed on identifying EoLC

priorities; and suggestions for improvement to the documentation. Common themes included; time required completing documentation, ability of the patient to engage in deciding priorities, the environment, current format of the documentation, initiating such conversations, realism in meeting identified priorities, emotional impact at a time of vulnerability, and staff competence/confidence to address the issue with patients.

- Discussion during an education session post questionnaire

Ideas, opinions and themes shared by the registered nurses (n=11) at this event appeared to mirror the findings of the questionnaire, and assisted in identifying ways to improve upon the EoLC documentation.

- Establishing the patient's perspective

A comparison with staff views was made through a purposive sample of patients using an experience based design approach, to collect patient stories (n=4). It was acknowledged the small sample might not fully reflect the views of all the hospice patient population. Key themes identified were; surprise that individuals were able to talk through end of life priorities with staff; an increase in confidence to discuss with family/carers; clarification of treatment options and implications; feelings of relief; timing of the conversation in relation to the patient's illness; difficulties in imagining a situation they had not yet experienced and the comfort of decision making e.g. final arrangements, so that families/carers did not have the burden.

Although the project aim was not fully met, data collated has informed further discussion in hospice practice and publication of a revised EoLC document.

Implications for practice:

- The initial poor response rate to the staff questionnaire may have been due to directly questioning staff integrity in managing this aspect of patient care despite guarantees of anonymity
- The project provided opportunities to consider just how it felt to explore issues around EoLC with patients and to reflect back upon the process as staff
- Despite initial enthusiasm by the multidisciplinary team for the project it became apparent that maintaining momentum would rest with the project team alone
- Each patient was offered the opportunity to record their thoughts and feelings in a Patient Experience Log prior to interview but elected to tell their story instead
- Staff placed a high value on identifying a patient's preferred priorities for EoLC and patients expressed the importance of having a healthcare professional to talk this through

A full project report including references can be accessed from: <http://www.fons.org/library/report-details.aspx?nstdid=16845>.

This project was supported by the FoNS Patients First Programme in partnership with The Burdett Trust for Nursing.