



An holistic approach to nutrition and diet in palliative care

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Project background

Dorothy House Hospice is a charitable organisation based in Winsley, Wiltshire. Holistic palliative care is offered to patients who have a life-limiting illness with complex palliative care needs and their carers. The facilities include a 10-bed inpatient unit, a day patient unit and two outreach centres in the community.

This project was influenced by two separate but related issues. On the one hand, external regulation governs the fulfilment of nutritional requirements. On the other, there are the complex and varying needs of palliative patients in this respect, where the 'goal of nutrition therapy may NOT be weight gain or reversal of malnutrition, but it should be about quality of life' (Macmillan Cancer Support, 2007).

Aims and objectives

The aim of the project was to develop and implement an appropriate nutritional screening tool for palliative care patients that would be acceptable across all settings and meet the expressed needs of patients and carers. To achieve this aim, the objectives identified were to:

- Identify and engage stakeholders in the project
- Explore the lived experience of palliative care patients and their carers in relation to eating and drinking
- Use the information gained from the stakeholders, especially the patients and carers, to guide the project and the development of an appropriate tool to enhance nutritional care
- Use a practice development framework to implement changes in practice
- Evaluate the changes in practice and their impact on patient experiences, and adapt the tool where necessary

Implications for practice

- Meaningful collaboration is possible even in difficult settings such as hospices
- Patient and carer stories will reveal sometimes unexpected views and priorities
- Practice development initiatives can produce unexpected benefits

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

Key activities and outcomes

• Multidisciplinary nutritional steering group (NSG)

The multidisciplinary NSG, which included a hospice volunteer and a patient, recognised everyone with direct or indirect involvement in day-to-day nutritional care for patients as stakeholders, including clinical staff, kitchen staff and volunteers. In order to develop a joint team statement of values and beliefs with regard to nutrition, the project team decided to use a values and beliefs clarification questionnaire with all stakeholders. The response rate was high, although it was more difficult to engage clinical nurse specialists based at local outreach centres.

• Patient and carer interviews

An explanatory leaflet, a consent form and a set of open-ended questions were developed by the NSG. After a successful pilot with one patient and a carer, four semi-structured interviews were conducted to explore patients' and carers' feelings about nutrition at the end of life and its impact on their wellbeing. The recordings were played in full to the NSG to guide its discussion and planning. The main themes to emerge from the interviews were the need for smaller portion sizes for those who have little or no appetite, the variety of meals available each week, the difficulty of eating with fickle taste changes and the importance of the social aspect of eating.

• The development of the Patient Led Assessment of Nutritional Care (PLANC) tool and algorithms

The PLANC tool and algorithms were developed after listening to patients and carers, and built on the tools in the Macmillan Durham Cachexia Pack (tinyurl.com/durham-cachexia). It was agreed that a screening tool that required further assessments or weighing patients would not be suitable for the hospice setting, and that it also had to take into account carers' needs. The dietitian and the ward staff agreed to a three-month trial and audit comparing PLANC with the standard MUST tool (tinyurl.com/must-calc) to establish if PLANC was as good as or better than MUST at helping to plan appropriate nutritional care for palliative care patients and their carers.

• Outcomes

The dietitian's evaluation of PLANC versus MUST showed little difference in the care plans produced for patients in the inpatient unit in the early stages of palliative care. However, the benefit of PLANC was that it could still be used appropriately at the end of life, unlike MUST. Perhaps more importantly, inpatient unit staff felt that using PLANC enabled conversations with relatives that would not otherwise have taken place and felt overwhelmingly that it was more appropriate for their patients. The catering staff in particular were drawn into the project; they were able to connect with patients and their needs and had many practical ideas on how to meet those needs.

Dorothy House is in the process of rolling out PLANC across the organisation. The hospice at home carers also listened to the interviews and, while they do not undertake formal assessments, felt they had a much greater understanding of the emotional impact of loss of appetite and weight loss on patients and carers.