

# Choice and decision-making in palliative care: a study of patients', carers' and health care professionals' experiences

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Executive Summary

This research report was compiled by researchers from the Sue Ryder Care Centre for Palliative and End of Life Studies at the University of Nottingham. Specialist palliative care services have succeeded in transforming the care and treatment that patients receive at the end of life. However, many individuals and their families still do not have access to the relevant supportive and general palliative care to meet their needs and these issues have been acknowledged with a plethora of new initiatives. These initiatives demonstrate a number of key issues and gaps in the research base relating to palliative and end of life care which include:

- Dying and the subsequent need for palliative care is difficult and not well understood
- Communicating with patients and their families and carers about the transition into palliative care is difficult with little guidance on what facilitates or hinders such discussions
- There is a lack of information relating to how conversations about place of care and death are initiated and facilitated and how choice is promoted
- While there is work which has identified preferences for place of care and death there is a lack of research which has sought to establish what happens to decisions made about these issues over time and at points of crises

In light of these issues, this report captures the views of patients faced with a life limiting illness as well as their professional and informal carers in both cancer and non-cancer groups (heart failure) across a range of care settings in the Mid Trent region and its impact on patient and families' experiences of that palliative care. The study design was a multi-site, prospective, longitudinal survey. Five care areas were selected for the purposes of sampling. An initial review conducted provided information relating to the scope and range of palliative care provision for both cancer and non cancer populations across each of the five study sites. The choice of areas ensured that palliative care provision across a range of areas was covered and allowed for comparison across care boundaries. The care services selected included a GP practice, a heart failure community matron service, a

hospital specialist palliative care service, a nursing care home and a hospital heart failure clinic. The research team reviewed each team's caseload between January 2005 and December 2006 using a service audit tool developed for use in the study. This data provided information as to the range and scope of activity of each team and allowed us to audit the care provided to patients in the last 4 weeks of life.

In order to access patient, carer and health care professionals' experiences of palliative care provision, up to 10 newly referred patients to each of the teams were also selected for inclusion in the study. For each patient who agreed to take part, a patient nominated family member was also approached to take part. Subsequent data collection involved interviews with the patient and family member at two to three further time points over the course of their illness. Focus groups with each of the five teams in the study were also conducted alongside a number of individual staff interviews. The aim of the focus groups was to explore perceptions and experiences of service providers with respect to end of life care: especially in terms of local delivery/impact of the End of Life Care Programme. Focus group data served to contextualize findings from the audit: elucidating approaches to record-keeping and identifying disparities between reported and recorded practice as well as providing information about trigger points for referral into palliative care.

Interviews and focus groups were transcribed and analysed qualitatively with the aid of the qualitative data analysis package NVIVO. A series of main categories and associated sub-categories of the data were then constructed that captured the main dimensions of the areas discussed in the interviews. Each interview was initially analysed by the research team member who undertook the interview. Caseload and audit information for each team was entered into SPSS for a basic descriptive analysis. Derived description of the recent activities of each team enabled individual cases to be considered in relation to their care context. Analysis of audited records produced a descriptive profile of care received in the last four weeks of life and facilitated evaluative comparisons.

Through the process of auditing case service records, we found that there was a lack of systematic recording of advance care planning discussions. We also found there to be substantial variability in terms of the content, depth, and location within case notes of recorded discussions. For cases without evidence of advance care planning/discussions, it was generally unclear as to why discussions were not recorded. As a consequence, this may cause problems for patients when they move between services or the care of different professionals within the same service. Whilst it is possible to conceive of a more systematic approach to record keeping of advance care discussions, it is recognised that health care providers could easily become over-burdened with record-keeping.

We discerned that for the majority of cases with a recorded preference, the sampled services enabled the patient to realize their preferred place of care (typically, their home/permanent residence) and that case services were generally achieving outcomes in line with the End of Life Care Programme. However, it was not clear how outcome rates had changed from outcomes pre-programme. There were a number of cases for which researchers encountered advance care discussions that were recorded prior to the last four weeks of life. However, these were not counted for the audit because they fell outside of the specified sampling window.

Participants acknowledged that an audit of records of patients' last four weeks of care did not fully reflect the realities of the delivery of services. Moreover, they also suggested that their record-keeping did not reveal the real depth of work undertaken, particularly around conversations held with patients around preferred place of care and other aspects of advance discussions. Reasons identified for the lack of recording these aspects of delivery of care included constraints of time and resources alongside the practicalities of maintaining fully comprehensive records of lengthy conversations.

On the whole, those patients who we spoke to stated a reliance on staff to initiate discussions about end of life care. Staff members stated that engaging in end of life care discussions exerted a toll on their own emotional wellbeing and regularly expressed concerns about taking the lead for fear of causing distress, taking away hope or touching on topics that the patient was not ready to engage with. Good interpersonal relationships were often seen as fundamental to discussions of this nature but, at the same time it was recognised that there were different levels of awareness and denial between patients and relatives alike. Moving between services at the

end of life also made it difficult to establish good interpersonal relationships based on trust. Several staff who we interviewed identified the need and usefulness of training in advanced communication skills; such training may also address one's own feelings about death and dying. Making the topic accessible may be preferable to not offering the opportunity for patients and carers to talk about their concerns. It was also interesting to note that issues such as advance directives, living wills and enduring powers of attorney were conspicuous by their absence in interviews with patients and staff.