Non-professional carers' views on the care of the dying in an acute trust; the impact of a simple end of life tool

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Aims The Department of Health's End of Life strategy promotes integrated care pathways for the dying as a means of improving end-of-life (EOL) care. The authors designed a pilot study to determine whether a simple EOL care tool could improve the dying experience in an acute hospital setting as perceived by carers.

Methods 40 patients received usual EOL care and 30 patients had their EOL care directed by the EOL care tool. Bereaved carers were contacted a month after the patient's death and asked to complete the validated VOICES questionnaire.

Results 20/40 questionnaires were returned by carers whose relatives received usual care and 18/30 by carers whose relative received care directed by the tool. Although numbers are small and therefore changes are not statistically significant, improvements were seen in the responses regarding medical and nursing care (43.8% of relatives rated nursing care as excellent in the usual care group compared to 83% in the EOL tool group). Benefits were seen in pain management (56.3% of carers perceived their relative had pain when receiving usual care vs 28% in the EOL tool group). Improvements were also seen in communication with more relatives feeling they were kept informed about the patient's condition in the EOL group than in the usual care group (64% vs 38%). More carers were present when their relative died following introduction of the tool (43.8% in the usual care group vs 67% in the EOL tool group).

Conclusion Non-professional carers reported improvements in some aspects of end-of-life care following the introduction of a simple EOL care tool. This needs further testing in an adequately powered trial.