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CO-ORDINATION OF GENERALIST END OF LIFE CARE IN THE UK: A MULTI-SITE ETHNOGRAPHIC STUDY

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ABSTRACT

Introduction and aims Appropriate, effective and timely generalist care for patients and their families towards the end

of life is recognised as an essential component of high quality, equitable care. Improving coordination of care is one of the core objectives of the UK Department of Health End of Life Care Strategy. We aimed to identify the contextual complexities and challenges to well co-ordinated care delivery for people towards the end of life in different generalist settings.

Method We used organisational ethnography among staff who were not specialist palliative care providers in three locations; an acute receiving unit, a respiratory outpatient clinic, and a primary care practice. The protocol included sustained interactions with health providers and interviews with patients and their carers over 9 months. The integrated datasets offer an understanding of how end-of-life care co-ordination is understood, initiated and conducted within patient trajectories and in the context of everyday healthcare provision.

Results The patient-centred, long term focus of primary care drives individual and team activity and requires flexibility and collaboration. In the secondary care short-term, acute setting, role boundaries and a clearly defined process, in which time constraints are paramount, may result in a less personalised experience for patients.

Conclusions Coordination of care for patients and their families with advanced progressive diseases undergoing emergency admissions or transition across settings is important. The level of coordination and the systems in place influences people's experience of coordination of generalist settings. Further research regarding how collaboration influences coordination of care is required.