Variations in out of hours end of life care provision across primary care organisations in England and Scotland

Executive Summary

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Published February 2013

This project is funded by the Service Delivery and Organisation Programme

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Project 08/1813/259
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This report should be referenced as follows:

Relationship statement:
This document is an output from a research project that was funded by the NIHR Service Delivery and Organisation (SDO) programme based at the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) at the University of Southampton. The management of the project and subsequent editorial review of the final report was undertaken by the NIHR Service Delivery and Organisation (SDO) programme. From January 2012, the NIHR SDO programme merged with the NIHR Health Services Research (NIHR HSR) programme to establish the new NIHR Health Services and Delivery Research (NIHR HS&DR) programme. Should you have any queries please contact sdoedit@southampton.ac.uk.

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Project 08/1813/259
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Criteria for inclusion:
Reports are published if (1) they have resulted from work for the SDO programme including those submitted post the merge to the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors. The research in this report was commissioned by the SDO programme as project number 08/1803/259. The contractual start date was in September 2010. The final report began editorial review in March 2012 and was accepted for publication in February 2013. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The SDO editorial team have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the final report documentation. However, they do not accept liability for damages or losses arising from material published in this report.
**Executive Summary**

**Background**

Timely access to high quality appropriate end of life care in the out of hours period has been reported to be a key factor in enabling patients at the end of life to be able to remain at home, if this is their wish. Deficiencies in out of hours end of life care have long been recognised. Most out of hours end of life care is provided by generalists: health care professionals who, although often expert in their own field, have not had specialist palliative care training. Research into generalist out of hours end of life care is limited. A scoping report on generalist end of life care funded by the National Institute of Health Service Delivery and Organisation programme concluded that research is needed ‘to define and evaluate models of generalist out of hours care at the end of life within a systems approach, taking account of different providers ... ’ Before research into this can take place, however, more information is needed about how this care is currently provided, about variations in service provision, and whether identifiable models of service provision exist from a systems perspective.

**Aims**

To establish how generalist out of hours end of life care is provided in the community; to explore variations in provision, including evidence for distinct models of care; to investigate views of commissioners and senior managers, in order to help inform commissioning decisions, and the direction of further research.

**Methods**

1. A qualitative telephone interview study with senior managers in Strategic Health Authorities in England and Heath Boards in Scotland responsible for end of life or out of hours care which explored participants’ views of service provision, its strengths and weaknesses.

2. A telephone interview survey of key informants knowledgeable about commissioning or providing out of hours end of life care in Primary
Care Organisations in England and Scotland. 50% of Primary Care Organisations in England and Scotland were sampled. Questions about the provision of out of hours end of life care services were coded and analysed numerically, and views on service provision, its strengths and weaknesses were analysed using qualitative methods.

3. An Expert Panel who discussed service delivery variations within these data, considered whether there were emerging care models, discussed ‘good’ out of hours end of life care characteristics, and began to develop theoretical propositions about out of hours end of life care.

4. A ‘Virtual’ User Panel which obtained views about preferences for, and experiences of, out of hours end of life care.

Results

Senior managers from 30% of Strategic Health Authorities/Health Boards participated in interviews (n=13). Response rate for the Primary Care Organisation survey was 42.8% (51 of 119 sampled Primary Care Organisations). Participating Primary Care Organisations in England probably had larger populations and GP practices than all Primary Care Organisations. 5/51 Primary Care Organisations were excluded from qualitative analysis because of inadequate data.

20 ‘experts’ in end of life or out of hours care were approached to participate in the Expert Panel: 14 agreed and 6 participated on the day. Professional roles included Strategic Health Authority Executive Nurse, Palliative Care Consultant, GP and GP commissioner, PCT Director of Commissioning, Lead Advisers for two national palliative care organisations, Technical Officer and GP out of hours database provider (one member had dual roles). Project team representation contributed expertise in out of hours and urgent care, primary palliative care, and an expert commissioning perspective. As planned, six service users participated in the ‘Virtual’ User Panel: two each with cancer, organ failure and with frailty.

The research has two main findings. Firstly, the importance of considering out of hours end of life care as a complex system which includes aspects of ‘in hours’ generalist end of life provision as well out of hours GP, urgent care, nursing and social care, and specialist care services. Secondly, that there is considerable variation amongst Primary Care Organisations in England and Scotland in both the type and level of provision of generalist end of life out of hours services and the use of mechanisms to facilitate end of life care.
Out of hours end of life care as a complex system

The study findings demonstrate that out of hours medical care is just one component, albeit an important one, of the out of hours services needed by EoL patients at home. This contrasts with previous research, which has focused on out of hours GP provision. They also illustrate the importance of viewing out of hours end of life care as a complex system. Data show, for example, how perceived deficiencies within one part of the system may be addressed by service innovations elsewhere, and how problems at one point in the system have implications elsewhere.

These results also show the extent to which good out of hours end of life care depends on actions within working hours. Good OoH EoL care cannot be separated from care within hours, and in-hours care must be seen as part of the out of hours end of life care system.

Variations in extent and type of service provision

All Primary Care Organisations reported that practices in their Primary Care Organisation had a system to notify out of hours GPs about end of life patients. 62% used fax/email and 38%, an electronic system. In only 18% of Primary Care Organisations did GP practices and out of hours organisations share the same electronic system, although a further 22% planned to do so. Respondents’ comments indicate that these figures represent the best picture within Primary Care Organisations. Not all practices used these systems regularly if at all; there were difficulties in getting information updated; and there were wide variations in how much information was shared, from name only through to full care plans, PPoC and DNAR. Less than half of ambulance services were able to access information on end of life patients. Respondents in several Strategic Health Authorities and Primary Care Organisations discussed implementation of an electronic palliative care register, and reported varied experiences.

Patients wanted the out of hours organisation to know about them to ensure informational continuity but, importantly, they wanted the out of hours system to work differently for them. They did not want to have repeat their information to different people, and found this difficult; they wanted prioritisation at triage and to be contacted by the clinician within a reasonable, specified, period. Some Primary Care Organisations did things differently in this respect, but no evaluations on the impact of different mechanisms were reported.

49% of responding Primary Care Organisations reported that District Nurses were available 24/7 consistently across the Primary Care Organisation, and the remaining 49% reported either partial provision 24/7 (for example at weekends or up to 10pm weekdays) or varying provision across the Primary Care Organisation. No previous studies have looked at the prevalence of
nursing and personal care services other than 24/7 community nursing services. These findings suggest considerable innovation in provision, and uncertainty, particularly in rural areas, about the feasibility of 24 hour district nurse services.

The Expert Panel agreed on five characteristics of ‘good’ out of hours end of life care. Only one in eight Primary Care Organisations had all five characteristics, with two fifths having four out of the five.

Conclusions

Implications for healthcare

Significant variations in out of hours end of life care, both between and within Primary Care Organisations, demonstrate that progress is still needed to ensure all end of life patients and families receive high quality out of hours care.

The evidence in this research suggests that the first two steps of the Department of Health end of life care pathway (i.e. Discussions as end of life approaches, and assessment, care planning and review) should be regarded as integral parts of out of hours end of life care, even though these steps usually take place during normal working hours.

There is variation both between and within PCTs in what information on end of life patients is notified to out of hours GP services, in the proportion of this which happens in ‘real time’ and, if not, how often it is updated. There is also variation between out of hours providers in what happens as a consequence of this information. This evidence suggests that the wishes of EoL patients and their families would be better met if more Primary Care Organisations met the standards of the best and improved their out of hours end of life care informational continuity.

Commissioners in this research were concerned about the impact of ambulance services through unscheduled admissions in EoL care. These services currently have poor access to information. It is unclear whether improved information would impact positively on patient experience, but this seems likely.

The evidence suggests uncertainty amongst NHS senior managers and commissioners about the feasibility of providing 24 hour District Nurse care, accompanied by a range of models for meeting patient’s nursing and personal care needs, and family respite needs, at night. Debate is therefore needed about available models and their perceived strengths, weaknesses and costs, in order to ensure that all end of life care patients receive appropriate care at home and avoid unwanted hospital admissions.
Recommendations for research

Research is needed into the

1) the most effective, efficient and acceptable models of providing care to meet end of life patients nursing and personal care needs out of hours, taking into account the impact on the whole out of hours end of life system.

2) the most effective, efficient and acceptable strategies to provide continuity out of hours for end of life patients and their families.

3) generalist out of hours end of life care as complex systems, including patient notification and advance care planning in normal working hours, from the perspectives of patients, families, staff and organisations; to explain the antecedents, impacts and consequences of differing OoH configurations in this context.

4) the most effective and efficient strategies to avoid unwanted hospital admissions following ambulance call-out for EoL patients who want to remain at home, and to ensure rapid hospital discharge when admission is unavoidable.

5) the costs of maintaining end of life at home out of hours compared to admitting them to hospital.

6) the most effective and efficient ways of providing education and training in end of life care for generalist staff working in out of hours services.