



OPEN ACCESS

Primary palliative care research: opportunities and challenges

Stephen Barclay,¹ Emily Moran,¹ Sue Boase,¹ Margaret Johnson,¹ Roberta Lovick,¹ Jonathan Graffy,¹ Patrick L White,² Brenda Deboys,³ Katy Harrison,⁴ Brooke Swash¹

¹Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK

²Department of Primary Care and Public Health Sciences, King's College London, London, UK

³Clinical Research Network Eastern; Primary Care, Cambridge, UK

⁴Cambridgeshire and Peterborough NHS Foundation Trust, Fulbourn, UK

Correspondence to

Dr Stephen Barclay, Primary Care Unit, University of Cambridge, Cambridge CB2 1TN, UK; sigb2@medschl.cam.ac.uk

Received 3 September 2018

Revised 15 December 2018

Accepted 16 January 2019

ABSTRACT

Introduction Primary care has a central role in palliative and end of life care: 45.6% of deaths in England and Wales occur under the care of primary care teams at home or in care homes. The Community Care Pathways at the End of Life (CAPE) study investigated primary care provided for patients in the final 6 months of life. This paper highlights the opportunities and challenges associated with primary palliative care research in the UK, describing the methodological, ethical, logistical and gatekeeping challenges encountered in the CAPE study and how these were addressed.

The study methods Using a mixed-methods approach, quantitative data were extracted from the general practitioner (GP) and district nurse (DN) records of 400 recently deceased patients in 20 GP practices in the East of England. Focus groups were conducted with some GPs and DNs, and individual interviews held with bereaved carers and other GPs and DNs.

The challenges addressed Considerable difficulties were encountered with ethical permissions, with GP, DN and bereaved carer recruitment and both quantitative and qualitative data collection. These were overcome with flexibility of approach, perseverance of the research team and strong user group support. This enabled completion of the study which generated a unique primary palliative care data set.

INTRODUCTION

Over 500 000 people die each year in the England and Wales: 23.6% at home, 22.0% in care homes, 46.6% in hospital and 5.6% in hospices.¹ General practitioners (GP) and district nurses (DN) working in primary care teams are central to palliative and end of life care provision, with 45.2% of all deaths occurring under their care at home or in care homes. In the UK, patients are

registered with one GP practice who are responsible for providing care to that patient in the community, either at home or in a care home. There are separate DN teams, often based in different buildings to GPs, and often working with several GP practices. While the National Health Service (NHS) policy asserts that most people would prefer to die at home² as suggested by previous literature reviews,^{3,4} it is now recognised that many are not asked or do not express a preference.⁵ Preference for home death is heavily contingent on adequate nursing support, symptom management and home circumstances⁶: home (and care home) can be 'the best place or the worst place to die.'⁷ NHS policy² emphasises facilitating patient choice and preferences, calling for 24/7 community care and free social care at the end of life.^{8,9}

Palliative care research in primary care is challenging, although few papers have described the practicalities and challenges of undertaking such research.¹⁰⁻¹² There is a comparative scarcity of primary palliative research¹³ with just 0.1% of the medical research budget allocated to palliative care.¹⁴ There is a pressing need for more research and for innovative methods to ensure that studies include the views and experiences of all involved: patients and their families as well as clinicians. Research into sensitive topics such as palliative care can encounter multiple recruitment barriers: clinician gatekeeping, priority given to clinical issues and concerns about raising research participation during sensitive consultations.¹⁵

The Community Care Pathways at the End of Life (CAPE) study investigated primary care provision for patients in the final 6 months of life. This paper describes the impact of the methods we



© Author(s) (or their employer(s)) 2019. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Barclay S, Moran E, Boase S, et al. *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/bmjspcare-2018-001653

used on participant recruitment and data collection in palliative care in the community. We consider the implications for the conduct of primary palliative care research.

THE CAPE STUDY

Twenty participating GP practices each identified 20 consecutive recent patient deaths, excluding trauma, suicide and those under age 18 years. The care provided by primary care teams during these 400 patients' last 6 months of life was investigated using multiple methods:

- A. Case note reviews of GP and DN records with supplementary GP and DN questionnaires to document care provision.
- B. Focus group discussions within practice teams: to explore practitioners' views of deceased patients' care.
- C. Interviews with bereaved lay carers, GPs and DNs: to investigate individual patients' care in greater depth.

Establishing the CAPE study

Ethical considerations

The collection of data from clinical records after death required additional research ethics permissions. Permission to access patient records after death, without their prior consent, lies outside the scope of NHS Local Research Ethics Committees. While the further ethical permission from the National Information Governance Board for Health and Social Care (now Health Research Authority Confidentiality Advisory Group) took several months, it enabled the creation of a novel data set of community care provision in the final 6 months of life.

Patient-identifiable data (name, NHS number, dates of birth or death) remained on practice premises, with only unique study identifier codes available to researchers off-site. To further ensure confidentiality and reduce potential bias from prior knowledge, data extraction from clinical records and bereaved carer interviews were conducted by different research team members. The study advisory group of clinicians, researchers and lay members advised that bereaved carers might be uncomfortable that their loved one's medical records had been accessed, despite our having ethical permission to do so. Patient and Public Involvement (PPI) members of the advisory group made a significant contribution to the submission of ethical applications. The role of PPI in ethical applications ensures that the research is accessible and applicable to a patient group, and can lend credence to applications for research approvals in sensitive areas such as palliative care.

GP practices were asked to identify individuals who had been close to the deceased patients and to minimise gatekeeping by including all those suitable for interview.^{15 16} Potential participants were approached by practices on behalf of the research team 6 months after bereavement, avoiding significant dates such

as birthdays or Christmas. Information concerning bereavement support services was given at interview, highlighting the role of GP practices, with a telephone call made a few days after interviews to check on participants' well-being.

Conducting research with bereaved people is highly sensitive, potentially placing a burden on participants at a vulnerable time. Several bereaved carer participants reported benefit from taking part and sharing their experiences: none reported interviews to have been unhelpful, adding to evidence that many bereaved people welcome the opportunity to be involved in research and may receive benefit from doing so.¹⁷ Timing of interviews 6 months after death, avoiding sensitive dates and providing bereavement support information helped create a safe environment for participants to discuss the care of their loved one.

Recruiting GP practices and DN teams

Few difficulties were encountered in recruiting the 20 GP practices, in large part due to strong support from Clinical Research Network (CRN) colleagues, who were familiar with local practices and arranged payments to GP practices. Purposive sampling recruited a diverse sample of practices across the East of England by: urban, rural and market town populations; practice age structure, ethnicity and social deprivation.

DN team recruitment proved much more challenging, despite DN managers being involved in the funding application and study design throughout. While warmly supportive in principle, fieldwork took place during a time of considerable change and uncertainty in DN teams with changing providers, high workloads and staffing shortages. In contrast to GP practices, CRN colleagues had little success in their recruitment approaches to DN teams. DN teams were more willing to participate when approached through the recruited GP surgeries. Personal explanations of the limited commitment involved reassured several who had initially been put off by the study paperwork. It eventually proved possible to recruit each DN team linked to the 20 participating GP practices, although considerable flexibility in recruitment approaches was needed.

The context within which recruitment is undertaken cannot be ignored. As stated above, DN teams were operating within an environment of considerable uncertainty and pressure which impaired their ability to commit to a research project. The research team ensured that expectations of time commitment were clear and realistic and were flexible to accommodate the realities of the local DN landscape. It should be noted that these observations relate to UK NHS practice.

Despite successful recruitment of all GP surgeries and DN teams, participation of individual team members varied. GP practice agreement to participate was often

made by a managing partner or one GP. This did not always guarantee participation of all GPs in the practice. In all, 123 GPs from 20 practices were involved in the study. Although we sought participation by the GP most involved with a patient, an alternative GP was sought when the patient's main GP declined to participate. In some DN teams only one nurse knew the deceased patients due to colleagues moving posts or long-term illness. This often resulted in one nurse taking on all aspects of the study.

Data collection

Documenting primary care provision

In phase 1 data were extracted concerning GP and DN care provision for patients in the final 6 months of life from their GP and DN records. All participating GP practices readily provided access to their GP records. Administrative staff printed copies of the electronic GP records and give access to missing data such as medications.

Access to DN records was more challenging. Most teams used patient-held paper records. Some were untraceable, being either unlocatable in external archiving facilities or thought to be still in the deceased patient's home. Occasionally portions of DN paper notes were missing. Fuller records were obtained from the few DN teams that used electronic records in addition to paper notes in the home. Based on GP records, the DN records that we had access to and GP reports, we estimate that 202 (51%) of the 400 deceased patients received DN care on at least one occasion during the final 6 months of life, of which we were able to obtain data for 134 (66%; 33% of total). In time, increasing use of shared electronic health records should mitigate these difficulties.¹⁸

GP practices used several computer systems, only some of which contained information from other services such as specialist palliative care, speech and language therapy and physiotherapy. In practices using other information technology systems, evidence of such services' involvement was only available in letters or GP comments. Analysis therefore focused solely on GP and DN care. A full picture of care would require accessing the records of all potential services, including hospital and hospice records, which was outside the remit of the study. Data were missing for cause of death for 34 patients: this was obtained from the General Register Office.

Data were extracted into a study-specific database for all recorded patient interactions with healthcare services in the last 6 months of life. They were categorised by location (GP surgery consultation, telephone consultation, outpatient appointment, inpatient admission, and so on), healthcare professional involved (GP, DN, consultant, healthcare assistant, and so on) and days before death. For 22/400 (5.5%) patients, GP records were not available for the entire final 6 months of life, having been previously registered with another

practice whose records were not accessible. This was particularly the case for those transferred to a nursing home at the end of life. This meant that while 100% of clinical records were provided by the GP practice with which the patient was registered at death, a portion of these records for the final 6 months of life was not available to the research team.

GPs and DNs completed a brief questionnaire for each patient concerning if/when/why the patient had been identified as approaching the end of life, key indicators of decline and additional community services such as specialist palliative care nursing and social care. Replies were obtained for 388/400 (97%) GP and 118/202 (58%) DN questionnaires.

Obtaining healthcare professionals' perspectives

After data extraction from records, focus groups were held in 10 practices, discussing in each the care of five practice patients, purposively selected as a maximum variety sample (cancer/non-cancer, gender, age group and degree of GP and DN involvement). Between 2 and 10 participants, mainly GPs and DNs, with some other clinical staff took part: timetabling for scheduled educational or multidisciplinary team meetings ensured optimal attendance.

In the other 10 practices semistructured interviews were held with bereaved carers, GPs and DNs for two patients per practice (one cancer, one non-cancer) with whom there had been significant primary care team input. Carer interviews explored perspectives on care provision for the deceased, both as recipients of care and as proxies for the deceased. GP interviews were problematic to schedule: practice staff at times booked appointments without the GP knowing the purpose and occasionally arranged a 10 min surgery appointment. It was common for one DN to engage with the study on behalf of their team. At times he or she was the sole DN completing all questionnaires and participating in the focus group or the two interviews. Some DN teams covered more than one participating GP practice, creating a DN participant burden that delayed scheduling interviews.

Obtaining bereaved carer perspectives

Practice teams found it difficult to identify bereaved carers. After searching deceased patients' records and checking informal practice knowledge, no lay carer was identified for some: for others carers' names were known but not their addresses as they were registered with different GPs or non-resident with the patient. Carer recruitment was initially very poor: in the first five practices, of the 21 bereaved carers invited, 4 (19%) agreed, 6 (29%) declined and 11 (52%) did not respond. The study user group was invaluable here, suggesting that potential participants may have felt intimidated by the bulky and official-looking study information pack: they suggested that a less formal initial brief letter be sent in handwritten envelopes,

with the full participant information sheet subsequently mailed to those interested in participating. They also advised that non-response to the initial approach letter did not indicate refusal and that a follow-up letter after 1 month was appropriate. These changes, approved by the Local Research Ethics Committee, had a profound effect on participation: of the subsequent 15 carers invited, 87% agreed (two after the follow-up letter), 13% did not respond and none declined. We achieved an improved carer response rate by avoiding overburdening people with official-looking information at the first approach and sending reminders giving additional opportunities to respond. This resulted in markedly improved response rates overall, yielding 17 carer participants, 47% of those approached.

Thus with flexibility and persistence it proved possible to recruit bereaved carers, GPs and DNs, obtaining their differing perspectives on individual patients' care.

DISCUSSION

The CAPE study generated a unique quantitative and qualitative data set concerning GP and DN care in the final 6 months of life. Taking a GP practice-based population approach, the care of a diverse group of 400 patients at end of life was documented, highlighting solutions to the challenges facing primary palliative care provision and research in UK NHS primary care.

The data set is limited to GP and DN care provision. It was not possible to consistently access information concerning other care providers such as social carers, specialist palliative care, care homes, hospitals or hospices. Clinical records are variable in their completeness, although records are more complete for sicker patients, such as those at the end of life.¹⁹ However, we were able to source all missing cause of death data and were able to access GP records for 100% of patients, with a 97% completion rate for GP questionnaires. It must also be acknowledged that this work was conducted in England, and the applications are therefore primarily applicable to the UK health-care system. This raises the question of whether or not some of the challenges encountered are due to the way in which healthcare is organised in the UK, or whether these are challenges that are innate to palliative care research. In countries where the DN and GP services are not aligned, there are likely to be additional challenges associated with coordinating a large-scale study such as this.

While acknowledging these limitations, the account of 400 patients' care in the final 6 months of life, to be presented in future papers, is a large, rich and unique data set that would be very difficult to obtain by other methods. Clinical record data extraction did not rely on Read-coded data as in most large database studies: the text was examined in detail, a time-consuming process. A similar approach has been used in Scotland, where to facilitate after-death analysis in groups

of GP practices²⁰ in Scotland, a GP researcher visited the practices and extracted anonymised data which streamlined and helped standardise data collection.

Difficulty in accessing DN records and securing DN involvement in focus groups or interviews has been reported by others. Continued DN use of paper-based records, kept in the patient's home, was problematic: where electronic DN records were kept, access was far easier. It has been stated that nursing lacks the research culture of medicine.²¹ We found repeated reorganisation, loss of administrative support and lack of computerised records to exacerbate difficulties in DN engagement. Time pressures, a lack of confidence in completing the research tasks and viewing the study as potentially critical of their care were additional barriers for DNs. Reassurance around time commitment and support from senior management facilitated engagement with the study. Despite considerable workload pressures and staff shortages, many were keen to share their experiences of palliative care. DN perspectives are central to primary palliative care service delivery and research. It is critical that their participation is enabled by researchers and managers.

Bereaved carer recruitment difficulties were effectively overcome following discussion with the study advisory and PPI groups whose suggestions of an informal initial approach and reminders might be usefully considered. PPI group members were emphatic of the importance of giving bereaved people an opportunity to engage with research: those who participated often commented that interviews had been helpful in giving them an opportunity to discuss their experiences with someone impartial and to 'give something back'.

The experience of the CAPE study adds to a developing literature concerning the challenges of palliative care research. Others have emphasised the importance of flexibility and creativity in improving recruitment rates.²² While gatekeeping continues to be a challenge to recruitment,¹⁵ we found that working closely with staff fostered a shared interest and ownership of the study that successfully enabled GP practice, DN team and carer participation. In the development of primary palliative care interventions, guidelines for evaluating complex interventions in end-of-life care relevant to primary care are available and are useful for intervention studies.²³

CONCLUSION

This paper highlights the challenges experienced in conducting palliative and end of life care research in the community, which it is hoped will be of use to others undertaking similar research in the future. Persistence, flexibility, strong PPI support and a strong mutually supportive research team can enable many of the barriers to be overcome. Future papers will present the quantitative, health economic and qualitative data obtained.

Acknowledgements The authors are grateful to the coapplicants who have supported the work of the CAPE study: Simon Cohn, Irene Higginson and Paul McCrone. Angela Harper, PA to the Cambridge Research Group, provided invaluable support throughout the study. In addition, the authors recognise the help and support of our PPI group, whose time and input was invaluable: Roberta Lovick, Margaret Johnson and the late Joan Fields.

Contributors SB was the principal investigator and designed the study with PLW and JG. EM, SB and BS undertook data collection and data analysis. MJ and RL were members of the PPI group. BD and KH supported GP practice and community nursing team recruitment. All authors met regularly as members of the study advisory group throughout the project, supporting recruitment, data collection, data analysis and interpretation. All have contributed to the manuscript and have approved the final version.

Funding This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0909-20323). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. BS received funding from the NIHR School for Primary Care Research (SPCR). SB is supported by the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England at Cambridgeshire and Peterborough NHS Foundation Trust.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

REFERENCES

- Office for National Statistics. *Mortality statistics: deaths registered in England and Wales: 2017*. London: Office for National Statistics, 2018.
- Department of Health, 2008. End of life care Strategy. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf
- Higginson IJ, Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000;3:287–300.
- Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332:515–21.
- Hoare S, Morris ZS, Kelly MP, *et al*. Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *Plos One* 2015;10.
- Thomas C, Morris SM, Clark D. Place of death: preferences among cancer patients and their carers. *Social Science & Medicine* 2004;58:2431–44.
- Parkes CM. Home or hospital? Terminal care as seen by surviving spouses. *J R Coll Gen Pract* 1978;28:19–30.
- The Choice in End of Life Care Programme Board, 2015. What's important to me. A review of choice in End of Life Care. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf
- House of Commons Health Committee. *End of life care: fifth report of session 2014–15*. London: The Stationary Office, 2015.
- Harris F, Kendall M, Murray SA, *et al*. *What are the best ways to seek the views of people affected by cancer about end-of-life issues?* London: Macmillan Cancer Relief, 2005.
- Barnes S, Gott M, Payne S, *et al*. Recruiting older people into a large, community-based study of heart failure. *Chronic Illn* 2005;1:329.
- Payne S, Brearley S, Milligan C, *et al*. The perspectives of bereaved family carers On dying at home. *BMC Palliative Care* 2012;11.
- Murray S, Barclay S, Bennett MI, *et al*. Editorial: palliative care research in the community: it is time to progress this emerging field. *Palliative Medicine* 2008;22:609–11.
- The End of Life Care Coalition, 2016. On the brink: the future of end of life care. Available: <http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-WEB.pdf>
- Ewing G, Rogers M, Barclay S, *et al*. Recruiting patients into a primary care based study of palliative care: why is it so difficult? *Palliative Medicine* 2004;18:452–9.
- White C, Hardy J. Gatekeeping from palliative care research trials. *Prog Palliat Care* 2008;16:167–71.
- Crowther JL, Lloyd-Williams M. Researching sensitive and emotive topics: The participants' voice. *Res Ethics* 2012;8:200–11.
- Petrova M, Riley J, Abel J, *et al*. Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from. *BMJ Support Palliat Care* 2018;8:455.
- Weiskopf N, Rusanov A. Sick patients have more data: the non-random completeness of electronic health records. *AMIA Annual Symposium Proceedings Archive* 2013:1472–7.
- Tapsfield J, Hall C, Lunan C, *et al*. Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners. *BMJ Support Palliat Care* 2016. [Epub ahead of print: 13 Apr 2016].
- Lamb D. Nurturing a positive research culture: The academic department of military nursing perspective. *J R Army Med Corps* 2015;161(Suppl 1):i6–9.
- Boland J, Currow DC, Wilcock A, *et al*. A systematic review of strategies used to increase recruitment of people with cancer or organ failure into clinical trials: implications for palliative care research. *J Pain Symptom Manage* 2015;49:762–72.
- Higginson IJ, Evans CJ, Grande G, *et al*. Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC Med* 2013;11.