Thinking ahead about medical treatments in advanced illness: a qualitative study of barriers and enablers in end-of-life care planning with patients and families from ethnically diverse backgrounds

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Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/JVFW4781.

Primary conflicts of interest: Louise Wallace was member of the DH Service Delivery and Organization Evaluations Panel (2009-11), the DH NIHR Health Services & Research Development Panel (2012-13), the HS&DR Researcher Lead Panel (2013-16) and the DHSC Health and Social Care Delivery Panel-(Seacole) (2019-22).

Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Published June 2023
DOI: 10.3310/JVFW4781

Scientific summary

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Health and Social Care Delivery Research 2023; Vol. 11: No. 7
DOI: 10.3310/JVFW4781

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

This study explored the experiences of terminally ill patients from ethnically diverse backgrounds and their family caregivers (FCGs), and whether or not, and how, they think ahead about deterioration and dying and the nature of their engagement with health-care professionals (HCPs) in end-of-life care planning (EOLCP). We have explored diversity in approaches to decision-making and the barriers to, and facilitators of, discussions and planning for future deterioration.

The National Institute for Health and Care Excellence quality standards and national policy and guidance require that HCPs offer patients with advanced disease an opportunity to have open and honest conversations about their illness and its prognosis, and to engage in shared decision-making, including anticipatory EOLCP, thereby enable personalised care at the end of life and equitable access to palliative care services. Thinking ahead about decisions and preferences related to anticipated deterioration may help people be cared for in the way, and in the place, that they prefer. However, little is known about the nature of ethnically diverse patients' preferences for end-of-life care (EOLC) or how the current EOLCP policy, paradigm and practice 'fit' with diverse cultural values and beliefs.

In addition, evidence indicates that many HCPs lack confidence both in engaging in EOLCP and in supporting ethnically diverse patients and their families generally, and lack training and development in this area.

Aim

The aim of this study was to address the research question: what are the barriers to and enablers of ethnically diverse patients, FCGs and HCPs engaging in EOLCP?

Objectives

1. To explore how terminally ill patients from ethnically diverse backgrounds, their FCGs and the HCPs who support them think ahead about deterioration and dying; to explore whether or not, and how, they engage in EOLCP; and to identify barriers to and enablers of this engagement.
2. To explore the experiences and reflections of bereaved family caregivers (BFCGs) on EOLC, and the role and value of thinking ahead and of engagement with HCPs in EOLCP.
3. To identify information and training needs to support best practices in EOLCP and to produce an e-learning module available free to NHS and hospice providers.

Patient and public involvement

Patient and public involvement (PPI) is a central characteristic and strength of this project; it ensured that the study was grounded in the concerns and experiences of patients and FCGs, and conducted in an appropriate and sensitive manner. PPI was instrumental in the development of the study research question and the funding application, the design and development of the study materials, recruitment through community engagement, enhancing the interpretation of data, co-creation of outputs and dissemination of findings. The project team included a PPI co-applicant and a public, carers and bereaved relatives research consultee group.

Design and methods

This qualitative exploratory study recruited participants into three workstreams (WSs) between February 2019 and May 2021.

- Workstream 1: longitudinal patient-centred case studies, triangulating different data sources, including baseline and follow-up interviews over 6–9 months with a patient, their FCG and a HCP nominated by the patient, and a review of clinical records. Patients in seven participant identification centres (general practices, acute hospitals, hospices, community services/self-referral) were first approached by a HCP who was known to them.
- Workstream 2: a single interview with BFCGs who had experienced the loss of a family member from advanced illness in the previous 3–12 months. Participants were approached by a HCP known to them or contacted the research team themselves.
- Workstream 3: public and professional stakeholder responses to the themes of WS1 and WS2 in facilitated virtual workshops or written workbooks.

Participants for WS1 and WS2 and most participants for WS3 were intentionally recruited in Nottingham, Nottinghamshire, Leicester and Leicestershire. Additional academic stakeholder participants for WS3 were recruited nationally. Awareness about the study was promoted through a range of strategies including local Clinical Research Networks, e-mails, flyers, websites, Twitter (Twitter, Inc., San Francisco, CA, USA), an extensive programme of community engagement events and local radio.

We purposively sampled participants to achieve heterogeneity in key attributes and to construct a matrix that may be important for attribution of themes/subthemes and in our search for examples of variance within the data.

Recruitment was facilitated through translated materials and interviews were conducted in the preferred language of the participant. Most interviews were conducted in the patient's or FCG's home or the place of work for HCPs, but some were conducted by telephone, principally because of the COVID–19 restrictions.

Data analysis

Each data set in WS1 and WS2 was subject to both separate and integrated analysis through the method of constant comparison. Patient-centred case studies triangulated different stakeholder perspectives and data sources.

A pragmatic thematic analysis of each WS3 workshop field note was conducted, coding data into themes and subthemes relating to the specific questions addressed in each workshop through a process of constant comparison. To ascertain how the HCPs in WS3 discussed the practices around thinking ahead and EOLCP, additional analysis of workshop field notes used two implementation science approaches: behaviour change techniques and normalisation process theory. The identified techniques informed the content of the learning resource.

Research findings

A total of 115 individual participants were recruited to the study.

In WS1, there were 18 patient case studies, comprising 93 interviews. Seven case studies comprised interviews with patients, their FCGs and their HCPs; the others comprised two of the three perspectives. Four patients died and one case study includes post-bereavement interviews with two

FCGs. We interviewed 11 HCPs nominated by patients, all of whom were nurses. Four of the case studies required at least one participant to be interviewed with the assistance of an interpreter.

Nineteen participants were recruited to WS2. One participant was interviewed in Punjabi, all others in English. Fifty participants were recruited to WS3; 37 attended a workshop discussion and 13 completed a workbook.

Demographics

The age of the participants in WS1 ranged between 40 and 96 years. The majority (n = 11) had cancer. Eleven of the participants were female. Ten participants described their ethnicity as Indian, three described it as Caribbean and two as African. The remaining participants described themselves as Pakistani, former Yugoslavian and Chinese. Participants described their faith as Christian (n = 7), Hindu (n = 6), Muslim (n = 3), Jain (n = 1) and Buddhist (n = 1). Their living and social circumstances were quite diverse. The majority (n = 8) lived with a spouse, three lived alone as a sole adult and four had dependent children. Two lived with their adult children.

Nineteen BFCGs were recruited, of whom two self-referred. Thirteen were female and six were male. The majority described their ethnicity as Indian (11/19), four described their ethnicity as African Caribbean, two as Pakistani, one as British Indian and one as British Asian. Seven of the BFCGs were spouses and eight were children, with others being siblings (n = 2), a grandchild (n = 1) and a daughter-in-law (n = 1). The majority of the deceased people had had cancer [n = 11 (58%)], and they described their faith as Hindu (n = 8), Muslim (n = 6), Christian (n = 4) and Sikh (n = 1).

Of the 50 participants in WS3, 18 were members of the public (lay or community or faith leaders), 19 were HCPs, seven were academics and six were educators.

Findings of the case studies and bereaved family caregivers (workstreams 1 and 2)

Although there is, mostly, overall satisfaction with care, participants generally did not articulate strong relationships with professionals; some indicated a lack of trust and experienced a disjointed system, devoid of due regard for them.

The predominant stance of patients was to live with hope, in the now, and not overly contemplate the future; when they did contemplate the future, this tended to orientate to practical matters of wills and funerals, rather than the business of dying. The future was difficult to predict, and so pointless to plan for; moreover, for some, thinking ahead, and especially planning ahead, was counter to their values and faith. In contrast and tension with this was when the family had lacked awareness of how gravely ill the patient was. Here the occurrence of unexpected deterioration and death could be a devastating experience, following which participants could feel regret that they had been denied the chance to prepare and to make the best use of the time they had remaining.

End-of-life care planning discussions

Health-care professionals sought to identify when patients were ‘ready’ for EOLCP discussions and to accompany patients in this illness trajectory. In contrast, when clinical urgency necessitated immediate discussion, FCGs told of the harshness and impact of this, especially if it involved them acting as translators for their loved one.

Accounts of patients and families detailed the challenges in information-sharing about prognosis and discussions of treatments, seeing prognostic uncertainty as professional avoidance and nihilism, and some expressed concern that treatments were being withheld. Uncertainty was fundamental to patient and FCG experience of illness. Some participants used this as a justification for optimism, others for a more negative or fatalistic stance. The response to uncertainty mediated ‘readiness’ for future planning. The predominant position of HCPs, that of balancing physical burdens and benefits of treatments, was only sometimes shared.

Decisions about treatment

Some had set limits to future care, including cessation or rejection of treatment, such as dialysis or pain relief. Others were clear that they wished to receive all available treatment for as long as possible, and for professionals to make every effort to prolong life, including resuscitation. Participants’ responses were strongly influenced by past experience and observation of others. Several participants expressed a concern that certain treatments, including resuscitation and pain relief, would be either administered or withheld in a deliberate attempt to shorten life. The desire for active treatment was attributed, in some cases, to religious beliefs, but was also expressed by patients who had no religious convictions.

End-of-life observances

Religious and cultural mores for this life and the next were of great importance to many and there were anxieties about how the system valued and enabled these adequately. Family duty and community expectations in care were foregrounded in some accounts. This, coupled with complexities related to migration, revealed considerable hardships and distress. Concern about being in the (un)care of strangers was common.

Findings from stakeholder workshops and workbooks (workstream 3)

Laypeople and community and faith leaders identified that the key, and possibly insurmountable, barriers to EOLCP were religious fundamentalism, community pressure and cultural expectations. Previous negative health-care experiences also led to a lack of trust of professionals and organisations. Cultural and religious literacy of organisations and individual professionals was seen as lacking, as was accurate understanding of communities about end-of-life services.

Effective communication was seen as a key enabler, both in translation between languages and also in the use of accessible concepts and terminologies. In addition, information shared by trusted sources was seen as an important element to enhance care. Personalising care required additional ways of getting to ‘know’ the person (their sociocultural–spiritual context) and an openness to seeing and doing things differently.

The development of confidence and skills in supporting people when the ‘usual’ way of doing things is not adequate is needed; evidence-based stories were seen as a powerful training tool to this end. A number of behavioural change techniques pertinent to this were identified, such as setting staged goals with families to ensure an agreed approach to challenges ahead, and facilitating social support within the wider family context for the patient and immediate carer.

A strong message from the findings is that HCPs and other stakeholders regard genuinely integrated interprofessional working as key to providing more effective EOLC to patients and their families from diverse ethnic backgrounds.

Conclusions

Good EOLC is care aligned with patient preferences. Truly personalised care requires engagement with the differing values, beliefs and choices of individuals. The findings indicate that what constitutes a good end of life and a good death is influenced by the intersectionality of a number of complex factors, including, but by no means limited to, those of beliefs and culture. All people desire care that is personalised, compassionate and holistic, and the frameworks for good palliative care support this. However, HCPs need additional skills to navigate complex, sensitive communication and to enquire about spiritual values and aspects of people's lives with which they may be unfamiliar. The challenge for HCPs and services is in the delivery of this holistic care framework and the additional range of skills that are required to do this.

The nuanced, and changing, preferences for information, decision-making and care in the accounts and experiences of the participants indicate that only a focus on outcomes that relate to care being personalised, compassionate and holistic will address inequity. What constitutes a useful and safe discussion about the future may look and feel different when underpinned by specific paradigms about life, illness and death. Offering opportunities for information and discussion about a person's illness and situation was valued by many, but not by all, of the participants, and the level and timing of that discussion, and who that discussion is held with, must be navigated with skill.

Implications for practice

End-of-life care planning and related documentation is seen in policy as the predominant vehicle for enabling good end of life, but this may be in tension with the preferences of patients.

Systemic support needs to be more effectively attuned to the values and sociocultural contexts of patients and families, and provide continuity to deliver on personalised care.

Health-care professionals require high-level skills to navigate complex, sensitive communication and interpersonal relationships that foster appropriate discussions and planning for anticipated deterioration. This could be fostered by an integrated team approach, which includes members with skills in language and cultural bridging or advocacy.

Recommendations for research

1. How can HCPs identify if/when a patient is 'ready' for anticipatory discussions of deterioration and dying?
2. How can discussions about uncertain recovery and the need for decisions about ceilings of care, especially resuscitation, be most effectively conducted in a crisis?
3. How can professionals recognise and respond to the diversity of faith and cultural practices and to the heterogeneity of beliefs and preferences relating to EOLC between individuals from different ethnic groups?
4. What are the implications of an understanding of collectivist and relational models of care and decision-making for current UK health policy and practice, and their focus on individual choice, autonomy and anticipatory planning?
5. How can conversations be most effectively conducted when translation is required to enhance patient understanding.

Study registration

This study is registered on the research registry (researchregistry6161).

Funding

This project was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme and will be published in full in *Health and Social Care Delivery Research*; Vol. 11, No. 7. See the NIHR Journals Library website for further project information.

Health and Social Care Delivery Research

ISSN 2755-0060 (Print)

ISSN 2755-0079 (Online)

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb (ProQuest LLC, Ann Arbor, MI, USA) and NCBI Bookshelf.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as Health Services and Delivery Research (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr.

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This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number 17/05/30. The contractual start date was in November 2018. The final report began editorial review in December 2021. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house 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 document. However, they do not accept liability for damages or losses arising from material published in this report.

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