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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Disclaimer: "This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers."

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A final version (which has undergone a rigorous copy-edit and proofreading) will publish as part of a fuller account of the research in a forthcoming issue of the Health and Social Care Delivery Research journal.

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Scientific Summary

Background

This study explored the experiences of terminally ill patients from ethnically diverse (ED) backgrounds and their family care givers (FCGs) and whether and how they think ahead about deterioration and dying and the nature of their engagement with healthcare professionals (HCPs) in end-of-life-care planning (EOLCP). We have explored diversity in approaches to decision-making and the barriers and facilitators to discussions and planning for future deterioration.

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NICE 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, to engage in shared decision-making including anticipatory EOLCP, and 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 ED patients' preferences for end-of- life- care (EOLC) or how the current EOLCP policy, paradigm and practice 'fit' with diverse cultural values and beliefs.

Additionally, evidence indicates that many HCPs lack confidence both in engaging in EOLCP and in supporting ED patients and their families generally and lack training and development in this area.

Aim

To address the research question:

What are the barriers and enablers to ethnically diverse patients, family care Givers and health care professionals engaging in end-of-life-care planning?

Objectives

1. To explore how terminally ill patients from ED backgrounds, their FCGs and the HCPs who support them, think ahead about deterioration and dying, whether and how they engage in EOLCP and identify barriers and enablers to this engagement.
2. To explore the experiences and reflections of bereaved FCGs on end-of-life-care, 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 (PPI)

Patient and public involvement is a central characteristic and strength of this project in ensuring that it was grounded in the concerns and experience of patients and FCGs and conducted in an appropriate and sensitive manner. PPI was instrumental in the development of the study research question and funding application, the design and development of the study materials, recruitment through community engagement, enhancing the interpretation of data and in co-creation of outputs

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and dissemination of findings. The project team included a PPI co-applicant and a Public, Carers and Bereaved Relatives research consultee group (PCBR).

Design and methods

This qualitative exploratory study recruited participants into three Work Streams between February 2019 and May 2021

Work Stream 1 (WS1): Longitudinal patient-centred case studies, triangulating different data sources including baseline and follow up interviews over six-nine months with a patient, their FCG and an HCP nominated by the patient and a review of clinical records. Patients in seven participant identification centres (GP practices, Acute hospitals, hospices, community services/self-referral) were first approached by an HCP that was known to them.

Work Stream 2 (WS2): A single interview with BFCGs who had experienced the loss of a family member from advanced illness in the previous three to 12 months. Participants were approached by an HCP known to them or by contacting the research team themselves.

Work Stream 3 (WS3): 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 in 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 (CRN), emails, flyers, website, twitter and an extensive programme of community engagement events and local radio.

We purposively sampled participants to achieve heterogeneity in key attributes and 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 HCP but some were conducted by phone, principally due to COVID -19 restrictions.

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Data analysis

Each data set in WS1 and WS2 were 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 notes was conducted coding data into themes and sub-themes 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 (NPT). The identified techniques informed the content of the learning resource.

Research findings

115 individual participants were recruited in the study.

In WS1 there were 18 patient case studies which comprised 93 interviews. Seven comprised interviews with patients, their FCG's and their HCP's the others comprised two of the three perspectives. Four patients died and one case study includes post bereavement interviews with two FCG's. In eleven of the case studies HCPs interviewed were nurses. 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.

In WS2 19 participants were recruited. One participant was interviewed in Punjabi, all others in English. In WS3 50 participants were recruited, 37 attended a workshop discussion and 13 completed a workbook

Demographics

The age of the participants in WS1 ranged between 40 and 96 years old. The majority (n=11) had cancer. Eleven of the participants were female. Ten participants described their ethnicity as Indian, three as Caribbean, two as African. The remaining 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. Although the majority (n=8) lived with a spouse, eight lived as a sole adult and four had dependent children. Two lived with their adult children.

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Nineteen bereaved family carers were recruited of whom two self-referred. Thirteen were female and six male. The majority described their ethnicity as Indian (11/19), four as African Caribbean, two as Pakistani, one each as British Indian, and British Asian. Seven were spouses and eight were children with others being siblings (n=2), a grandchild (n=1) and one a daughter-in-law (n=1). The majority of the deceased people had cancer 11 (58%) and faith described 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 HCPs, seven Academics and six were Educators.

Findings of the case studies and bereaved family care givers (WS1 and WS2)

Although there is mostly overall satisfaction with care our findings indicate that participants generally did not articulate strong relationships with professionals and some indicate a lack of trust and experience 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 and where they did this tended to orientate to practical matters of wills and funerals rather than the business of dying. The future was difficult to predict so pointless to plan for and moreover for some thinking ahead and especially planning ahead was counter to their values and faith. In contrast and tension with this was where 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.

EOLCP discussions

HCPs sought to identify when patients were 'ready' for EOLCP discussions and accompany patients as this evolved through their illness. In contrast when clinical urgency required immediate discussion FCGs told of the harshness and impact of this, especially if 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 considered treatments were being withheld. Uncertainty was fundamental to patient and FCG

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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 (WS3)

Lay 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 healthcare experiences also built 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 the key enabler both in the translation between languages but also of use of accessible concepts and terminologies. Additionally, information shared by trusted

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sources was seen as an important element to enhance care. Personalising care required additional ways of getting to 'know' the person (their socio-cultural-spiritual context) and an openness to seeing and doing things differently.

Development of confidence and skills in supporting people where the 'usual' way of doing things is not adequate is needed and 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 end-of-life care to patients and their families from diverse ethnic backgrounds.

Conclusions

Good end- of- life care is care aligned with patient preferences . Truly personalised care requires engagement with the differing values, beliefs and choices of individuals. Our 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 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 our 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 our participants and the level and timing of that discussion and who that discussion is held with, must be navigated with skill.

Implications for practice:

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EOLCP 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 socio-cultural contexts of patients and families and provide continuity in order to deliver on personalised care.

Health 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 health professionals 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 as well as the heterogeneity of beliefs and preferences relating to end of life care 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 where translation is required to enhance patient understanding.

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Governance and approvals

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