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Understanding patient views and experiences of the IDENTIfication of PALLiative care needs (IDENTI-Pall): a qualitative interview study protocol

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ABSTRACT

Introduction More people are living with multimorbidity, defined as two or more long-term physical or mental health conditions. Multimorbidity is associated with poor quality of life and high treatment burden. Palliative care identification tools have been developed for use in primary care to seek out patients who could benefit from a palliative approach to their care. There has been little evaluative research on such tools; patient perspectives on the process of identifying their palliative care needs is a significant gap. The aim of this research is to provide new understanding into patient perspectives of the experience of having their palliative care needs identified, and the impact on their healthcare.

Methods and analysis This qualitative study will employ semistructured interviews to elicit the views of participants. We will purposively sample 10–12 adults with advanced serious illness who have been identified by their primary care team as having palliative care needs, and/or are receiving care from specialist palliative care services. A family member or carer may be included in an interview at the participant's request. A descriptive, thematic analysis will be carried out using the data analysis software NVivo.

Ethics and dissemination Ethical approval has been granted by the North of Scotland Research Ethics Committee. Study findings will be disseminated in peer-reviewed journals and through conference presentations. Other activities include the development of patient-centred outcomes for clinical practice and policy in relation to the use of palliative care identification tools.

Trial registration number National Institute for Health Research (NIHR) Clinical Studies Portfolio, UK Clinical Research Network (UKCRN) Study number 51296.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The qualitative approach will facilitate in-depth exploration of the views and experiences of patients of the identification of their palliative care needs.
⇒ This study will provide insights and understanding into the process of identification of palliative care needs from a patient perspective, addressing a significant gap in the current evidence base.
⇒ People who cannot provide informed consent in English are excluded from participating. This reduces the diversity of the study population.
⇒ There are multiple potential sources of potential bias including recruitment bias and unconscious bias from the researcher.

and emergency healthcare services.[2] The last 12 months of life (the 'end of life') and dying can be difficult to identify and predict.[3]

The World Health Organisation (WHO) defines palliative care as an 'approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual'.[4] People with multimorbidity and unpredictable illness trajectories could benefit from a palliative approach to their care.[5] Early identification of palliative care needs has the potential to improve care with its focus on quality of life and what matters most to patients and families. In terms of healthcare, this may include the opportunity to describe their wishes and preferences for care, and to consider referral to specialist palliative care services, where available.[6]

There is growing interest in the potential to proactively search for patients with palliative care needs in primary care.[7–9] The aim of searching for patients in this way is to seek out in a timely manner those patients who could

INTRODUCTION

More people are living with multimorbidity, defined as two or more long-term physical or mental health conditions, including symptom complexes such as frailty.[1] Multimorbidity is associated with poor quality of life, high treatment burden and polypharmacy. People with multimorbidity can suffer unpredictable, rapid deteriorations in health from a relatively stable to a life-threatening condition, resulting in frequent use of urgent

benefit from a comprehensive needs assessment and palliative approach to their care. At least 10 different palliative care identification tools and processes have been developed for use in primary care, including the development of tools to search electronic patient records.[9] However, there has been relatively little validation or evaluative research on these tools. To date, three systematic reviews have concluded that current palliative care identification tools and processes are limited in their ability to accurately identify patients who could benefit from palliative care in the primary care setting.[9–11] Further research is needed to understand whether such tools and processes can be implemented effectively, what the benefits are, and for whom. Such a nuanced area of practice has been the subject of public scrutiny and in 2017, the poor reliability of the 'surprise question' attracted significant media interest,[12 13] with concerns raised that people were 'missing out on palliative care' or 'told they were dying too early'.[14 15]

Research to investigate the perspectives of patients about the process of identification of their palliative care needs is a significant gap in the evidence base to inform the use of current tools. Understanding of the perspectives and experiences of people who may be subject to the use of such tools and other processes to identify palliative care needs should be central to the implementation of these tools and processes. The proposed research aims to provide understanding into the process of identification of palliative care needs, including the acceptability and feasibility of search tools, from the perspective of patients with advanced, incurable illness who have been identified as 'palliative'. The research will provide new insights and understanding into their experiences and perspectives, and any benefits and drawbacks they perceive of having their palliative care needs identified.

Aims and objectives

The overall aim of the study is to investigate the views and perceptions of patients with incurable illness about the identification of their palliative care needs.

The study objectives are:

1. To understand the experience of patients whose palliative care needs have been identified, and the implications for their healthcare.
2. To investigate the facilitators and barriers to the use of a tool to highlight unmet palliative care needs from the patient's perspective.
3. To propose policy and practice relevant recommendations for the use of palliative care indicator tools.

METHODS AND ANALYSIS
Study design

Qualitative research methods will be applied to conduct this in-depth exploration of the experiences of patients in relation to the identification of palliative care needs and what this means to them. The study will employ individual, semistructured interviews as they are an appropriate

method for exploring potentially sensitive subjects such as palliative care.[16 17] Interviews will gather information on the ideas, concerns, expectations and actions of individuals, and the context in which their views and behaviours are formed. These are influential factors that affect how a person may react to receiving a 'palliative' diagnosis, or a referral to specialist palliative care services.

Study setting

The study site is Sheffield, South Yorkshire, UK. At the time of this study, there were 80 general practices across Sheffield arranged into 15 primary care networks. Sheffield is a diverse city with areas of significant socioeconomic deprivation and ethnic diversity. A range of palliative care services are available, including those provided by St Luke's Hospice and Specialist Palliative Care at Sheffield Teaching Hospitals.

Sampling and eligibility

The study will purposively sample patients in order to recruit participants with experience relevant to addressing the research questions.[18] The study population will comprise adults with any advanced serious illness who have previously been identified by their primary care team as having palliative care needs, and/or are receiving care from specialist palliative care services. The aim is to recruit participants with diverse personal and socioeconomic backgrounds and a range of conditions in order to provide differing perspectives on the potential benefits of receiving a palliative diagnosis or palliative care services.

Family members or carers of adults with identified palliative care needs may be included as participants if they are invited by a participant to be present at a research interview. Informed consent will be sought from both the eligible adult and their family member/carer prior to the interview so that any contribution they make can be included in the data analysis.

Inclusion and exclusion criteria

Inclusion and exclusion criteria are outlined in table 1.

Size of sample

The aim is to conduct 10–12 interviews to reach data saturation.[19] Given the uniqueness of the experiences of people with advanced serious illness, it is possible that new insights will continue to emerge through the interviews such that data saturation is not achieved. We will aim for saturation of the main themes from the data and identify emergent themes, which may form the basis of future research.

Recruitment

Potential participants will be approached by a member of their clinical team in the first instance. Clinical teams will be informed about the study through presentations at local general practitioner practice and research meetings (including those of the Sheffield primary care research clusters) and to individual clinicians at their request. The research team will not have access to potential

Table 1	Inclusion and exclusion criteria

Inclusion criteria	1. Adults (aged >18 years) with advanced serious illness who are under the care of a GP within Sheffield Clinical Commissioning Group who either:
	  a. Receive specialist palliative care services.
	  b. Are aware of (have had discussions about) palliative care, including inclusion on the practice palliative care register.
	2. Family carers (aged >18 years) of an eligible adult when they have been invited to take part in an interview by the participant

Exclusion criteria	1. Children and young people aged <18 years. 2. People with advanced serious illness or their family carers who are unable to participate in a conversational interview for any reason related to their condition 3. Family carers who have not been invited to take part in an interview by the participant 4. Adults who are unable to provide informed consent in English.
GP, general practitioner.	

participants' clinical care records, but members of general practice clinical care teams may use their existing access to patient records to identify potential participants and check whether they meet the inclusion criteria.

Clinical teams will be provided with participant information sheets to introduce the study to eligible patients and/or family members. Clinicians will introduce the study during a routine consultation, or by telephone or email. Participant information will be made available (1) electronically so it can be sent to patients and/or family members via text or email and (2) in paper form for those who would prefer the information to be sent to them by post. Participant information will include telephone and email contact details for the research team. Potential participants will be invited to contact the research team to express an interest in taking part in the study. Alternatively, they will be asked to give their consent verbally, or by text or email, to their contact details being shared with the researcher (IL) so that she can contact them. Once a potential participant has expressed an interest, the researcher (IL) will use their preferred method of contact to discuss their participation in the research, answer any questions and arrange a time for interview.

Consent

Informed consent will be obtained from all participants before an interview is conducted. An electronic consent form will be devised using the University of Sheffield's preferred platform, GoogleForms. This can be texted or emailed to a participant, or a paper version can be sent by post at the participant's request. Participants will be asked to complete the consent form either electronically or by returning a paper form by post prior to an interview, and consent will be confirmed verbally when the interview commences.

Data collection

Interviews will be conducted with individuals, or with the patient and a family member together depending on the preference of the patient, via telephone, video call or face to face, at a time and place of their choice (subject to any restrictions imposed by the COVID-19 pandemic).

Interviews will be carried out by the researcher (IL), who has experience of conducting qualitative interviews for research. Additional bespoke training and support will be available from the research team (SM, CM and NT) as required. To ensure that the study is completed within the timeframe, SM and NT will also conduct interviews if necessary. Interviews will be semi-structured, using a topic guide (online supplemental appendix 1) while allowing time and space for the participant to develop their own account. Each participant will take part in a single interview lasting approximately 40–60 min.

Interviews will be audiorecorded using an encrypted device with the participants' consent. Field notes will be made to include any additional comments or reflections by the researcher. Interviews will be transcribed in full by the researcher (IL), and personal identifiers will be removed from the data. Anonymised transcripts and field notes will be stored securely on a password-protected university hard drive. Audiorecordings will be deleted.

Data analysis

Qualitative data management software, NVivo (V.12), will be used to support data analysis. A thematic analysis of the interview data will commence alongside data collection using an inductive and iterative approach.[20] All data will be coded by the researcher (IL) and codes grouped into broad overarching themes.[16 21] The emerging themes will be considered in the context of palliative care provision from a micro (immediate clinical team), meso (local organisation) and macro (wider healthcare system) level perspective.[22 23]

Peer review will take place throughout the data analysis to reduce lone researcher bias, with regular meetings of the research team.[20] A selection of transcripts will be reviewed and independently coded by SM, and coding frameworks will be discussed and compared, allowing further development of codes and themes.

ETHICS AND DISSEMINATION

Ethical approval was granted in November 2021 by the NHS Health Research Authority following a favourable opinion from the North of Scotland Research Ethics Committee (IRAS ID: 305374, REC reference: 21/NS/0157).

Ethical considerations

Studies have shown the potential benefits to patients of taking part in qualitative research of this nature in palliative care.[24] The study is designed to ensure that the risks and burden associated with taking part in the study are minimal. If a participant experiences any difficulties during the interview, such as tiredness or distress, the interview will be halted, and if necessary, brought to an end. Adequate time will be given for debrief, and the researcher will provide information about local resources for support as required. Interviews will be carried out at a time and in a location that is convenient to the individual participant.

If a home visit is carried out to conduct an interview, this will be undertaken in line with the Health and Safety policy for lone working at the University of Sheffield.

Equity of access to the study

The study setting is Sheffield, South Yorkshire, which is a diverse city. Within the time and resource constraints of this study, interviews will be carried out with those who can provide informed consent and take part in an interview in English, including with participants for whom English may be a second language.

Dissemination

On completion of the study, the data will be presented as a paper for publication in a peer-reviewed journal and at relevant conferences, locally and nationally. When completing the consent form, participants will be offered the option to receive notification of the outcome of the study via a summary report to be sent by post or email.

An additional output of the project will be the development of patient-centred recommendations for clinical practice and policy in relation to the use of palliative care identification tools. Recommendations will be disseminated via academic papers and conference presentations as well as directly with groups of National Health Service commissioners and policymakers locally, regionally and nationally, at existing meetings. An infographic will be produced to summarise the study findings, with patient and public involvement advice. This will be shared with patients, carers and the wider public, including via social media.

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