

ORIGINAL ARTICLE

Cancer diagnosis, treatment and care: A qualitative study of the experiences and health service use of Roma, Gypsies and Travellers

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Abstract

Background: Early diagnosis and treatment are key to reducing deaths from cancer, but people from Black and Minority Ethnic (BME) groups are more likely to encounter delays in entering the cancer care system. Roma, Gypsies and Travellers are ethnic minorities who experience extreme health inequalities.

Objective: To explore the experiences of cancer diagnosis, treatment and care among people who self-identify as Roma or Gypsies and Travellers.

Methods: A participatory qualitative approach was taken. Peer researchers conducted semi-structured interviews ($n = 37$) and one focus group ($n = 4$) with community members in Wales and England, UK.

Results: Cancer fatalism is declining, but Roma, Gypsies and Travellers experience barriers to cancer healthcare at service user, service provider and organisational levels. Communication was problematic for all groups, and Roma participants reported lack of access to interpreters within primary care. Clear communication and trusting relationships with health professionals are highly valued and most frequently found in tertiary care.

Conclusion: This study suggests that Roma, Gypsies and Travellers are motivated to access health care for cancer diagnosis and treatment, but barriers experienced in primary care can prevent or delay access to diagnostic and treatment services. Organisational changes, plus increased cultural competence among health professionals, have the potential to reduce inequalities in early detection of cancer.

KEYWORDS

cancer care, cancer diagnosis, cancer treatment, early detection, health services, Roma, Gypsies and Travellers: qualitative

1 | INTRODUCTION

Around a third of cancer deaths are preventable by timely diagnosis and curative treatment, with early detection offering the best chance of long-term survival (NHS England, 2019). Current global

and UK policy focuses on improving the speed of diagnosis to provide cancer patients with curative treatment and raise survival rates (NHS England, 2019; Wales Cancer Network, 2016; WHO, 2002, 2018). Inequalities in cancer outcomes are well recognised; people with lower education and income who live in areas of deprivation

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have higher cancer incidence and mortality rates than more affluent groups (Singh & Jemal, 2017). UK studies have shown that people from Black and Minority Ethnic (BME) backgrounds lack awareness of cancer services (Elkan et al., 2007) and have more negative experiences of care (Pinder et al., 2016; Saunders, Abel, & Lyratzopoulos, 2014, 2015). BME people experience more delays in entering the cancer care system, caused by factors such as symptoms not being recognised (Quaife et al., 2015; Waller et al., 2009) and delayed referral to secondary services from primary care (Lyrtatzopolous et al., 2012). Research has shown that Gypsies and Travellers have worse health outcomes than other ethnic minorities and those living in similar socio-economic circumstances in the UK (Peters et al., 2009; van Cleemput & Parry, 2001), but relatively little is known of their experiences of cancer diagnosis, treatment and care.

Roma, Gypsies and Travellers make up the largest ethnic minority in Europe (FRA, 2016), and Acton et al., (2016) estimate that there are 125,000 to 250,000 Gypsy/Travellers and around 200,000 immigrant Roma in the UK. The majority of UK Roma migrated from Eastern European countries that acceded to the European Union in the 2000s, although some arrived earlier as refugees from racist persecution (Greenfields, 2017). While the linguistic and cultural diversity of Roma, Gypsies and Traveller groups is recognised (Cook et al., 2013), they are politically and socially grouped by virtue of their common histories of nomadism and extreme disadvantage (WEC, 2019). Throughout Europe, Roma and Gypsy/Travellers experience discrimination and unequal access to employment, education and health care (FRA, 2014, 2016). Health data for these ethnic groups are not collected within the National Health Service data dictionary (WEC, 2019) but research has shown that Roma and Gypsy/Travellers share poor health outcomes (Cook et al., 2013) and healthcare access (Parry et al., 2007). Like other BME groups (Elkan et al., 2007; Fazil 2018), culture and language pose barriers to health care for Roma and Gypsy/Travellers, accompanied by mistrust, low health literacy, organisational barriers (such as difficulties in booking appointments and waiting times) and economic barriers (McFadden et al., 2018).

Fazil (2018) highlights the difficulties of collecting ethnicity data and suggests health service data on 'Other White' groups are the most incomplete. Lack of data collection for Gypsy, Roma and Travellers means that some conditions, such as cancer, are 'hidden diseases' (Aspinall, 2014). In a self-reported survey, Parry et al., (2007) found low rates of cancer among Gypsy/Travellers compared with age-sex matched comparators, but van Cleemput (2018) suggests that late presentation and/or non-survival may contribute to this apparent low incidence. Several studies have explored UK Gypsies and Travellers' cultural beliefs about cancer, which are characterised by secrecy, stigma, fear, stoicism and fatalism (Berlin et al., 2018; Smith et al., 2020; van Cleemput et al., 2007). To varying degrees, these beliefs are also common among other BME groups (Licqurish et al., 2017) and among the general population (Robb et al., 2014; Vrinten et al., 2017). Millan and Smith (2019) point out that the impact of traditional beliefs on health outcomes is likely to be subordinate to that of widespread socio-economic inequalities.

Cancer fatalism is more common among the least educated and most socially disadvantaged (Quaife et al., 2015), and those from BME backgrounds (Vrinten et al., 2016). End-of-life care has been explored among Roma and Gypsy/Travellers, and commonalities are preferences for non-disclosure of diagnosis to the patient, care being provided by the extended family and death at home (Jesper et al., 2008; Roman et al., 2014).

This study adopted a participatory approach to explore views and experiences of cancer among people who self-identify as Roma, Gypsies and Travellers. By including Roma participants who are recent migrants to the UK, this study builds upon existing research into attitudes to cancer among UK Gypsies and Travellers, such as Berlin, Smith & Newton's seminal study (2018). Previous research demonstrates that engagement with vulnerable groups is facilitated by involving service users in addressing health problems that affect their communities (Liamputtong, 2007), and Földes and Covaci (2012) recommend involving Roma people in the design and conduct of research to better understand their needs. As previous research suggests cancer is a feared and stigmatised disease (Berlin et al., 2018; Roman et al., 2014; van Cleemput et al., 2007), this topic required an in-depth, sensitive and highly participatory approach, with community members were involved at all stages of the research process. This article focuses on cancer diagnosis, treatment and care, aspects of health care that are under-researched among these ethnic minorities.

2 | METHODS

2.1 | Design

A participatory qualitative study, using semi-structured interview and focus group methods.

2.2 | Recruitment and consent

Six peer researchers recruited participants from their own extended families or wider community networks. Only those peer researchers considered willing to discuss the topic of cancer (e.g. having family experience of cancer) were invited to participate. Most of those who received an invitation were interviewed, but a minority did not have time on the appointed day. Participants received an information sheet one week in advance of the interview (in translation for non-English speakers), plus verbal explanation. Written consent was obtained prior to data collection. Participants' received a supermarket voucher as a "thank you" for their time.

2.3 | Participants

Targets were set to obtain maximal variation within the sample (see Table 1). Age was a selection criterion to explore differences in

TABLE 1 Targeted and actual sample for age, ethnicity and gender

	Young people (16–25 years)	Adults (26–50 years)	Adults (over 50 years)	Men	Roma
Target sample (N = 35–50)	10–15	10–15	15–20	One third	One third
Actual sample (N = 41)	12 (29%)	16 (39%)	13 (32%)	11 (27%)	14 (34%)

BOX 1 Topic guide

- How is cancer viewed by you and people in your community?
- Do you know of anyone who has had cancer and could you tell us about it?
 - a. Diagnosis
 - b. Treatment
 - c. Care
- Who would you talk to about cancer?
- Is there anything else you would like to say about cancer?

perspective between generations. Roma people and men were targeted as they are underrepresented in qualitative research. Berlin et al., (2018) have previously highlighted the challenges of involving men from Traveller communities in qualitative research.

2.4 | Data collection

Peer researchers received training in qualitative research methods before carrying out semi-structured interviews and a focus group with members of their own communities. Questions were devised jointly by academic and peer researchers (see Box 1). Interviews were conducted face-to-face in participants' homes or meeting rooms. Roma interviewees spoke in Romanes or Slovak according to preference. A focus group was held with four Romanian Roma who preferred to be interviewed jointly, with a Romanian interpreter experienced in cross-cultural research providing translation for the Slovakian Roma peer researcher. Median interview length was 15 min (range four to 37 minutes) and the focus group lasted 40 min. All interview data were transcribed verbatim. Interviews conducted in Romanes and Slovak were transcribed and translated into English by a professional interpreter. To verify transcription and translation, two transcripts were checked against the audio-recording by a second interpreter.

2.5 | Data analysis and reporting

LC and DF analysed data, with input from JC and LM. Data analysis was guided by the Framework Approach (Ritchie & Spencer, 2002) which addresses applied social questions and provides a systematic and flexible way of managing large amounts of qualitative data (Gale

et al., 2013). A thematic framework was developed using a sample of interview transcripts, which was then systematically applied to the whole data set. Charts were produced for each theme, which were reviewed by peer researchers to ensure that the interpretation reflected the meaning during interviews.

2.6 | Reflexivity

Transparency about the characteristics of researchers and relationships within the research partnership contributes to the validity of qualitative research (CASP, 2006). LC and DF are female academic researchers, with experience in health inequalities (LC) and cancer survivorship (DF). LC had previously collaborated with two peer researchers and recruited others via third-sector organisations. Peer researchers (including JC and LM) were from Slovakian Roma and Gypsy/Traveller backgrounds, aged 18–58 years; four were female and two male. This diversity ensured the inclusion of a range of peer perspectives and facilitated recruitment.

2.7 | Ethics

The study was reviewed and approved by a University ethics committee.

3 | FINDINGS

Data were collected between October 2018 and March 2019 in South Wales and South-West England. Both Slovakian and Romanian Roma people were included in the sample and grouped as "Roma." People who self-identified as Gypsies, Travellers, Gypsy-Travellers or Showpeople were grouped as "Gypsy/Travellers." Showpeople travel with fairs and circuses and are within the broader "Gypsy/Traveller" classification. Table 2 provides demographic details of study participants.

Four superordinate themes were identified which influence access to health care and experience of cancer diagnosis, treatment and care. These are as follows: Stigma, Fatalism, Family and Healthcare Professionals. In the analysis below, similarities and differences are drawn out between the views and experiences of included groups (Roma, Gypsies and Travellers), in addition to those related to gender and age. In reporting direct quotations, the participant number (P1–P41), self-defined ethnicity, gender ([M]ale or [F]emale) and age are given; all names within quotations are changed.

TABLE 2 Participant demographics

Self-defined ethnicity	Sex	Age, years	Type of housing	Highest educational qualification
Gypsies, Travellers & Showpeople (n = 27)	Female: 20 Male: 7	Range: 18–77 Mean: 43	Caravan/chalet: 19 Housed: 8	No qualification: 16 GCSE: 4 Diploma: 4 Bachelor's degree: 2 Not stated: 1
Roma (n = 14)	Female: 10 Male: 4	Range: 19–58 Mean: 31	Housed: 14	No qualification: 2 GCSE: 9 A-level: 1 Master's degree: 1 Not stated: 1
Total (n = 41)	Female: 30 Male: 11	Range: 18–77	Caravan/chalet: 19 Housed: 22	No qualification: 18 GCSE: 13 A-level: 1 Diploma: 4 Bachelor's degree: 2 Master's degree: 1 Not stated: 2

Notes: GCSE: General Certificate of Secondary Education (school-leaving examination at age 16 years). A-level: Advanced level (examination at age 18 years). Diploma: Higher Education award below the standard of a Bachelor's Degree.

3.1 | Stigma

Both Roma people and Gypsy/Traveller spoke of cancer as a stigmatised disease, but noted views are changing:

If you had cancer you would never tell anybody, because that was something that people kept to themselves years ago.

P16-Gypsy-F,77

I know that there are such Roma who do not speak about it [but] there is no point feeling ashamed because of a sickness...it is not their fault, right?

P1-Roma-F,28

Participants varied as to the level of openness that existed within their own family, and some Roma and Gypsy/Travellers avoided saying the word 'cancer'. A grandfather's cancer was not spoken about much, 'not in front of women, or very many men', because he did not wish to appear 'weak before the community' (P22-Gypsy/Traveller-F,22). Shame was described as a deterrent to seeking medical help for symptoms (see Table 3).

Most Roma participants said they would promptly consult a doctor if they experienced symptoms, as did some Gypsy/Travellers. Symptoms such as unexplained bleeding or weight loss, fatigue, lumps and pain were well known, although some confused the side effects of cancer treatment with symptoms (e.g. hair loss). For some, pain was the only symptom that would motivate help-seeking. One elderly man described proactive help-seeking behaviour, while acknowledging that he could be an exception:

If I am ill, I goes to the doctor. And common sense is common sense...if you want to prolong things and stick pain for months and months then...it's too late.

P19-Gypsy-M,73

Roma people did not describe cultural barriers to seeking medical help for cancer symptoms, but widespread fear of being diagnosed with cancer. Fear was often related to long-term socio-economic consequences ('It is a serious and a financially challenging sickness, and it is mentally very hard' P25-Roma-F,57), not stigma. While stigma about cancer *per se* is declining, socio-economic vulnerability adds to fears of contracting the disease.

3.2 | Fatalism

While participants described fatalistic cultural beliefs, they did not necessarily hold these themselves. The 'older generation' were described as fatalistic about cancer, but in this study, old and young people displayed a variety of views. When considering whether cancer was curable or incurable, participants often expressed opposing views in one interview; however, Roma and Gypsy/Travellers agreed that the traditional belief was that cancer is usually incurable:

If it gets into a man, you can't get rid of it, and it's one in a thousand if you can make it.

P33-Roma-F,19

It's like a disease that Gypsies deem a bad thing...they know that it's a killer.

P7-Gypsy-F,55

TABLE 3 Barriers to accessing primary care with cancer signs and symptoms

Fear	<i>You should see a doctor for your health but some people are frightened to hear bad news. P41-Showperson-F,49</i> <i>I think a lot of people are afraid to go to doctors...I think that could be education or it could be apprehension to access these services, you know, because it's hard for them or they're not treated...seriously. P39-Traveller-M,33</i>
Shame	<i>A friend, he had it [bowel cancer] and he was very open...I'd be shy to talk about it and be shamed...if it did happen to me, I don't think I could go to the NHS. P13-Gypsy/Traveller-M,21</i> <i>There are intimate cancers, and you don't want to be talking about things like that with members of your family or other people or strangers, even to go to a doctor with it. P10-Gypsy- F,42</i>
Fatalism	<i>Some are very afraid of it and they think that they will anyway die...they do not feel like doing anything, because it is long-lasting and one must anyway die. P25-Roma-F,57</i> <i>If I said I think there's something wrong with you, he'd just go 'No, nothing wrong with me, I'm fine. If I die, I die. It's fine. It's my time to go, I go'. P37-Gypsy-F,28</i>
Difficulties in booking an appointment	<i>You phone up the doctors and you're either 12th in the queue and then it's very time-consuming and you've got children and work, so you just end up giving up. Or you do get through to the doctors and then you've got to wait days, weeks, even months. P17-Gypsy- F,30</i> <i>You call there and they say 'busy, busy, busy'. Even if you would go there, they tell you 'Make an appointment on the phone. Call!' And they give you the number too. But they would not say that I will make an appointment for you now...They do not say that. P5-Roma- F,19</i>
Unwelcoming services	<i>When you go to the doctor they don't like give you the information, they don't ask you questions. P6-Gypsy-F,68</i> <i>Even if you have flu, they will tell you not to go because 'it is a waste of time'...only when I get quite ill, when it is necessary, then I go. P3-Roma-M,23</i>
Communication difficulties	<i>I know that in the hospital whenever you say that you want to have one [an interpreter] they provide you one...at the GP, I do not know whether they provide one or not...I personally would not ask for it. P1-Roma-F,28</i> <i>They talks in a different way, language than what we do and we understand blunt words and they don't want to put them blunt words, but that's better for us if they did. P11-Gypsy/Traveller-F,48</i>
Delay in referral	<i>If they did more when she first went it wouldn't have spread like this...it was a locum doctor who...said, look, I am not happy about this; you've been coming back a long time...and I am going to send you for a Magic Eye. P7-Gypsy-F,55</i> <i>The doctor was adamant she never had cancer, and I said look, I want her tested for it...so we went for tests then. Yes, she had a tumour in her face. P11-Gypsy/Traveller-F,48</i>

Older people were often described as leaving it 'too late' to seek help for cancer symptoms, which led to a poor prognosis and confirmed the community view that cancer is always fatal. Reasons for delay in seeking help included lack of faith in doctors, lack of familiarity with modern treatments and low motivation. Several interviewees described Gypsy/Travellers acting promptly on children's health concerns, but becoming increasingly reluctant to seek help for their own symptoms as they aged. One woman said of her grandmother; 'Once her husband passed away she knew her illness had gone too far, so she just let it go' (P36-Gypsy/Traveller-F,38).

Understanding of cancer prognosis was sometimes sophisticated. A Roma man stated that the likelihood of survival was

related to the site and type of cancer, while a Showperson called for more research into pancreatic cancer 'because when it presents itself its usually too far gone to be treated' (P41-Showperson-F,49). Even the most disadvantaged young people (street newspaper sellers) were aware that early diagnosis would lead to better outcomes:

If you don't go to the doctor when it's small...it's aggravating and getting bigger.

P32-Roma-M,19

Participants were aware of cancer investigations (e.g. scan, biopsy and gastroscopy) and treatments, (e.g. chemotherapy, radiotherapy

and medication). Criticising old-fashioned taboos and fatalistic beliefs, one participant said:

You know, cancer's not a dirty word, it's an illness...
that mostly can be cured these days.

P10-Gypsy-F,42

However, a Traveller man argued that fatalism was justified because 'lack of access to services for a lot of people...and uneducated on the flipside as well' led to poorer health outcomes for Gypsy/Travellers than the majority population (P39-Traveller-M,33).

3.3 | Family

Most participants had experience of cancer in the family, and the exceptions were younger Roma. Extended families meant that many participants had extensive experience of cancer:

Me dad's youngest brother, he had bowel cancer. His sister...had cancer...Michael's brother had Hodgkin's... Pat's father had leukaemia in the bones. He had to have his leg off. And on me mum's side, her sister...she had leukaemia.

P15-Gypsy-F,69

Numerous examples were given of elderly relatives who had kept their illness secret, but most participants said they would now share a cancer diagnosis within the family circle. Families were described as exceptionally supportive; one cancer survivor said, 'with the Traveller community anything happens, everybody's there' (P18-Gypsy-F,59). A Roma woman described the family as the best support for mental distress experienced by cancer patients. When a family member was terminally ill, there was an expectation among Gypsy/Travellers that they would be cared for within the family:

We'll keep them home...we got daughters, granddaughters [to] look after the person that's ill.

P12-Traveller-F,60

Even in illness, privacy between men and women was maintained. One man commented that partners did not discuss sex-specific illness; 'We wouldn't talk about it to our wives, and they wouldn't talk about women's problems to us' (P40-Traveller-M,35). Despite obvious and worrying symptoms, such taboos might be too strong to be broken:

I think Billy was losing blood a long time ago...because I found it in the toilet. And I wondered where'd that blood come from because I never had no periods. But he had polyps.

P15-Gypsy-F,69

Women described men as reluctant to attend the doctors and attempted to encourage them to seek health care when necessary (see Table 3, Fatalism). Reluctance to engage with health services was often ascribed to men's breadwinner role, but many Gypsy/Traveller men referred to shame as the primary deterrent. Thus, despite the minority of men who resisted the stereotype of stoical Gypsy/Traveller masculinity, gender continued to influence help-seeking behaviours strongly in these communities.

3.4 | Healthcare professionals

Older participants said Gypsy/Travellers, including themselves, rarely used health services in the past but now would routinely consult a doctor. Generally, there was good understanding of the process of attending primary care with symptoms, then referral to secondary care:

If I might have it, the family doctor would...give me a referral in order to visit the oncologist.

P25-Roma-F,57

Obstacles to early detection were predominantly at the level of primary care (see Table 3). A good relationship with the doctor was seen as the gateway to accessing secondary services, but sometimes communication was problematic (see Table 3). Both Roma and Gypsy/Traveller participants gave examples of relatives who had repeatedly attended primary care with symptoms that later proved cancerous; this led to conflict when family members felt they had to pressure doctors to make a referral. Difficulties were exacerbated for non-English speaking Roma, some of whom had used a health insurance system in Slovakia and had little experience of primary care. A woman (who acted as an informal interpreter for friends and family) described dismissive treatment of Roma, which she attributed to discrimination. She reported being told by a nurse 'that I should not go to the hospital, because there are such doctors which do not want to help' (P5-Roma-F,19). No Roma participant reported access to interpretation in primary care, although this was available in hospitals.

Fear could be an obstacle to treatment, and two older relatives (a Gypsy Traveller woman and a Roma man) were reported to have refused cancer treatment, a decision that both later regretted. Some considered the side effects of treatment (such as vomiting and hair loss) as worse than the disease. However, three Gypsy/Travellers treated for cancer gave universally positive accounts of their care, as did many who had a relative with a terminal diagnosis. Specialist cancer services were described as good and healthcare professionals as kind and caring. Participants particularly liked those who built a relationship and expressed interest in their family. Plain speech that was easy to understand was much appreciated. Specialist nurses (from the Macmillan cancer charity) were described as accessible, reliable and non-racist, despite some fears they might "take over" care from the family:

Macmillan nurses are a godsend to all families, whether they be Travelling families, or house-dwelling families, because they're there, day and night, for any support that you may need...regardless [of] nationality.

P12-Traveller-F,60

Similarly, a local "hospice at home" service was liked because of their skills in working in partnership with families.

4 | DISCUSSION

Major advances have been made in cancer treatment worldwide, and in the UK, survival rates have doubled since the 1970s (CRUK, 2020). However, there is a persistent 'deprivation gap' in survival between the least and the most socio-economically deprived, and many lives could be saved if the most deprived had the same treatment and care as the most affluent (Ellis et al., 2012). Despite the implementation of national cancer strategies to reduce inequalities in cancer deaths, Exarchakou et al., (2018) found no evidence in England of a reduction in socio-economic inequalities in survival from 1996 to 2013. In Wales, the gap in cancer mortality between the least and most deprived areas increased by over 14% from 2001 to 2017 (NHS Wales, 2018). Although the incidence of cancer among Roma and Gypsy/Travellers is not known due to lack of routine data collection, their predominantly low socio-economic status (Cook et al., 2013), underuse of preventive health services (Peters et al., 2009) and high rates of smoking (ONS, 2014) are likely to increase their lifetime risk.

Barriers to health service use by BME people relate to service user and service provider attributes, and the organisation of health-care systems (Scheppers et al., 2006). In common with previous research, this study identified fear of cancer and cancer fatalism among service users (Berlin et al., 2018; Jesper et al., 2008; van Cleemput et al., 2007). As Robb et al., (2014) found in the general population, ideas about the curability/incurability of cancer could co-exist within one individual; similarly, among Gypsy/Travellers Smith et al., (2020) noted framing of cancer in terms of death, even when this was incompatible with real-life experiences. This study provides evidence that traditional Gypsy/Traveller beliefs, while widely known, have a decreasing impact upon individuals' behaviour. For women, cultural values of privacy and modesty remained a deterrent to help-seeking but did not override the decision to access primary care. Some young men expressed attitudes of stoical masculinity as reported elsewhere (van Cleemput et al., 2007), but even the most disadvantaged (street newspaper sellers) recognised that early diagnosis and treatment improve survival odds. Smith and Ruston (2013) suggest that Gypsy/Travellers are apt to rely on their own ethnic group for health advice, which adversely affects health outcomes. However, our study suggests that accurate information is available within Roma and Gypsy/Traveller communities about signs and symptoms of cancer, investigations and treatments, which may indicate rising levels of health literacy. Our findings clearly suggest

that Roma, Gypsies and Travellers are motivated to use health services for cancer diagnosis and treatment.

Service providers' attitudes and skills can enable or discourage service use (Scheppers et al., 2006). This study provided examples of what a good service looks like, mainly from tertiary care, where practitioners (nurses, doctors and third-sector workers) were described as forming relationships of trust with patients and their families and communicating clearly. Trust has previously been identified as key to establishing effective therapeutic relationships between service providers and Gypsy/Travellers (Lhussier et al., 2016; McFadden et al., 2018; Smith & Ruston, 2013). High satisfaction with specialist cancer services has previously been reported (Berlin et al., 2018; Smith et al., 2020), and in our study, the greatest dissatisfaction was expressed with primary care. Comprehension has repeatedly been reported as a barrier to healthcare use for BME people (Elkan et al., 2007; Fazil et al., 2015) and also among Gypsy/Travellers (Smith et al., 2020); our participants described struggling to understand medical terminology and feeling ashamed as a result. Van Cleemput (2018) ascribes the shame experienced by Gypsy/Travellers in medical settings to 'a devalued identity' that many experience because of widespread discrimination. Some Roma participants interpreted common UK health promotion messages, such as using primary care in preference to emergency care and avoiding unnecessary medication, as strategies intended to dissuade their health service use, and one described overt racism. Health providers can be uncertain and apprehensive when responding to the needs of people from ethnic minorities (Fazil et al., 2015), and their attitudes can be influenced by negative media stereotypes (Francis, 2013; van Cleemput, 2018). Cultural competence training for health professionals is frequently recommended; however, a risk is acknowledged that this can emphasise patient characteristics rather than service provider and system-level factors (Burt et al., 2016).

System-level barriers to ethnic minorities' health service use include opening hours, appointments and waiting time, length of consultation, translation and referral (Scheppers et al., 2006). Registration with a GP has been identified as problematic for Gypsy/Travellers due to discrimination (McFadden et al., 2018; van Cleemput, 2018), but was not raised in this study. For people living precarious lives (characterised by demanding and inflexible work, poverty and insecure housing) difficulties in booking appointments, though shared by all, act disproportionately to discourage access to health services (Scheppers et al., 2006). In addition, Gypsy/Travellers are more likely to have dependent children than the general population and to be an unpaid carer (ONS, 2014), factors which add to the difficulty of accessing health care in a timely manner. In the UK, primary care is the gateway for referral to secondary health services within which cancer is diagnosed and treated. In this study, some Slovakian Roma people were accustomed to a health system offering direct access to secondary care and hence had to adapt to a new system. Emergency care is one of the few services that migrant families use more than local populations (Markkula et al., 2018), and this 'overuse' has been the subject of negative comments in the British media (Hargreaves et al., 2006). Framing messages positively

(such as promoting what primary care can offer, rather than criticising Emergency Department attendance) may be effective in encouraging greater use of primary care, without stigmatising service users. Fazil et al., (2015) identified access to interpreters as the main area where service providers and policymakers fail to provide BME people with a basic quality of care. The need for language support extends to booking appointments and ringing for results as well as clinical interaction (Lehane & Campion, 2018), activities which contribute to early cancer diagnosis and treatment.

5 | STRENGTHS AND LIMITATIONS

A strength of this study was the participatory design. Involving peer researchers in all stages of the research process facilitated open communication about a sensitive topic. Employing a purposive sampling technique added to the rigour of this study, ensuring the representation of Roma people, both genders and a range of ages. Our study builds upon previous research into Gypsy/Travellers views of cancer (e.g. Berlin et al., 2018; Jesper et al., 2008) confirming some existing findings within a purposively selected sample, but also highlighting changing attitudes and differences between groups (particularly foreign-born Roma and UK Gypsy/Travellers). This is an important point as Roma, Gypsies and Travellers are diverse, but are often described as a homogenous group to the detriment of a nuanced understanding of their health and other needs (Women and Equalities Committee (2019). Liamputtong (2010) suggests that more accurate information is obtained when participants speak in their own language, but facilitating this is challenging for Roma people due to the wide variety of dialects and lack of Romanes-speaking interpreters; in our study, we were unable to recruit peer researchers fluent in the dialect of Romanian Roma. Gypsy/Traveller participants had an educational level consistent with the 2011 census sample (60% with no qualifications (ONS, 2014)); however, over 80% of Roma participants had at least one qualification, a level of education which may be atypical of the UK Roma community in general. Most Gypsy/Travellers in this study (70%) lived in a caravan or chalet, compared to 25% in the 2011 census, which limits generalisability to other Gypsy/Traveller groups.

6 | CONCLUSION

Despite policy initiatives to reduce the inequalities gap in England and Wales, disparities in cancer survival persist. In exploring the experiences of Roma and Gypsy/Travellers before and after diagnosis of cancer, this research presents a perfect storm of reasons for inequalities in healthcare access. While traditional beliefs about cancer as an invariably fatal disease are declining, poor experiences of care continue to support cancer fatalism. Barriers exist at the service provider and system-level, which reduce access to primary care and hence referral to secondary services. To encourage easy access for Roma, Gypsies and Travellers, health services need to be welcoming,

offer clear communication and interpreting as a basic right for non-English speakers. Organisational changes in primary care, plus increasing cultural competence among health professionals, have the potential to reduce inequalities in cancer detection and treatment.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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