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A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness

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Abstract

Aim To understand the experience of terminal illness and health care access for Gypsy Travellers, to inform palliative and primary care service provision.

Background Little contemporary research of UK English Romany Gypsy Travellers is available. This ethnic group is often overlooked in ethnic minority health research.

Methods Access to Gypsy Traveller communities was through non-health care channels and required the development of trust through repeated contact over time. English Romany Gypsy Travellers at two Traveller sites participated in face to face contacts. Data collection was through field observation, seven semi-structured interviews with Gypsy Traveller women and an e-forum discussion. The latter was members' only Gypsy and Traveller interest e-mail forum.

Findings The culture of Gypsy Travellers is distinct but diverse. Hygiene is important as is discretion and sensitivity to the information requirements of the patient and family. Gypsy Travellers are aware that their mobility (voluntary or enforced) can negatively impact on health care. Home care for the terminally ill is often preferred to hospital care often due to poor understanding of their cultural and personal needs and an aversion to 'bricks and mortar'. Care may be provided by the extended family. Palliative care provision should consider the needs of Gypsy Travellers including respect for their culture and support for caring at home.

The Health Experience of Gypsy Travellers in the UK:

A focus on terminal illness

(a) Introduction

According to written records, Gypsy Travellers have been resident in the UK since the 15th century and maybe even earlier¹. Throughout history, Gypsies have adapted and carved out their own economic niche. They have never expressed a yearning to become assimilated into house-dwelling society and have succeeded in protecting their cultural distinctiveness. At present, Gypsy Travellers are one of the most marginalised ethnic groups in the UK. Health research is sparse with the limited evidence available pointing to poor health status and poor access to health care²⁻⁷. Gypsy Travellers are not included in the national census⁸ or the Health Survey for England⁹. The health needs of Gypsy Travellers are invisible to policy makers as few of the relevant health service organisations in England collect data about their needs or include Gypsy Travellers explicitly in their policy statements or planning intentions⁷. In the UK, a review of health and health care for Gypsy Travellers demonstrated the need for improvement of their access to health services¹⁰. Both public and charitable health care provision in the UK, give considerable priority to palliative care¹¹ and recognise the need to provide services appropriate to the physical, psychological, social and spiritual care needs of ethnic minorities^{12 13}. However the particular needs of Travellers are not fully considered. The aim of this research was to understand the experience of terminal illness for English Gypsy Travellers.

(a) Methods

This study was undertaken with English Romany Gypsy Travellers in 2003/4 and included literature review, observational field work, semi-structured interviews and online discussion. There are a number of distinct travelling groups in the UK each with their own identity. This study focuses on English Romany Gypsies.

(b) Access

Accessing participants was challenging as Gypsy Travellers are a marginalised group and terminal illness and death is a sensitive subject. We were able to gain access to English Romany Gypsies over a period of 9 months involving approximately 20 days of researcher time with many unproductive contacts. Data collection focused on the experience of terminal illness as related by family/ community members with no attempt to recruit individuals in the terminal stages of illness. The literature on Gypsy Travellers indicate strict gender-defined boundaries and as the author undertaking the fieldwork was female (EJ), only female Gypsy Travellers were interviewed on this sensitive issue,

thereby respecting Gypsy Travellers' cultural norms¹⁴. This was confirmed during the study in the on-line discussion.

For two years, EJ joined an e-mail forum for Gypsy and Traveller issues with a membership of about 100 participants. This forum includes Gypsy Travellers and other traveller groups, people who work with or for Gypsies and academics. The forum is not public and those wishing to join are asked to give clear reasons. In order to protect the confidentiality of the e-mail forum, no identifying details can be given here. EJ corresponded with three Gypsy Travellers about her identity and intentions, before her admission to the forum.

(b) Observation

Field-notes were kept of observations. These informed the development of the research process and were analysed along with the other data. In addition to the time gaining access, the researcher spent approximately 20 days with Gypsy Travellers collecting data.

(b) Interviews

The researcher (EJ) established a relationship with each participant before initiating interviews. This was facilitated by a community worker and included many informal visits and a day trip to a Gypsy horse fair. The success of the interviews was reliant on a trusting relationship. During the fieldwork EJ became pregnant and this seemed to increase the participant's willingness to talk woman-to-woman. Regular contact was established with nine women and six of these agreed to interview. Two declined a formal interview although were happy to engage informally and one moved away.

Table 1 here (see appendix)

The semi-structured interviews covered experience of health care, family experience of terminal illness and disclosure of cancer diagnosis. They were very informal, often interrupted by the coming and going of children, and lasted 45 to 75 minutes. The interviews were conducted in the trailer (caravan) or shed (utility building) of the interviewee and all but one was audio-recorded.

(b) E-mail forum data collection

EJ followed discussion threads, gaining a better general understanding of the Gypsy Traveller perspective. The volume of e-mails ranged from 5 to 25 e-mails per day depending on current affairs. EJ participated in discussions on issues such as the link between ethnic monitoring, health surveillance and service provision. She asked questions to improve her understanding of language use, and initiated new discussion threads. The latter included the use of focus groups or individual interviews in the research, the dissonance between published literature on Gypsy Traveller culture and her field work, the ethnic profile of travelling people, and attitudes among Gypsy Travellers to figures of authority. Data from the e-mail forum contributed to the analysis presented

here. Extracts from e-mails of three e-mail forum members are quoted verbatim. EJ met with all three. They were all Gypsy Travellers: Richard O'Neil is a health campaigner, Linda (pseudonym) wishes to remain anonymous and LS joined the research team. All agreed to extracts of their e-mails being quoted in this paper.

The e-mail forum, once assured of the genuine motives for the research welcomed it and commended the research process. For example, in response to questions EJ posed to the e-group Richard O'Neil wrote:

“What you are doing is what I believe should be done, checking with Travellers about what certain people outside of our number have written about us. This information has often been cobbled together from previous reports with further second-hand information then being shoehorned to fit an already decided agenda or outcome. No wonder many people in government simply haven't got a clue.”
(Richard O'Neill)

Gypsy Travellers confirmed the unreliability of much of the early research undertaken. This quote provides insight into possible causes.

“...My Grandfather used to tell us about people, academics I suppose, who came to the camps in the 1st World War and after a period - who paid Travellers for info. My Granddad said they told them any old rubbish to get rid of them and draw a few bob!” (Linda)

(b) Analysis

The research team undertook a thematic analysis of data from all sources. When drawing conclusions the data were checked for confirming and disconfirming examples. Manual data processing was used.

(a) Results

The impact of accommodation issues on the life and health of Gypsy Travellers was all pervasive in the research data. Mobility was valued by the Gypsy Travellers as an important part of their culture. However, current UK law has increased enforced mobility. The results presented in this paper focus on the themes most pertinent to the experience of terminal illness for Gypsy Travellers including the role of the family, experience of the health service, the diagnosis of cancer, health beliefs about cancer and the experience of end of life care. However, their experience needs to be understood against the backdrop of their mobility and accommodation issues along with low levels of literacy.

(b) Cultural issues in health and illness

Throughout the research the importance of the family within Gypsy Traveller culture was clear. The extended family was important especially during illness or crisis. The

closeness of the family existed alongside a strong desire on the part of the individual to be discrete. This desire for confidentiality was striking. The data demonstrated the importance of propriety of conduct in Gypsy Traveller culture. There were clear gender defined boundaries for roles within the family. Both e-mail forum members and interviewees expressed a preference that sensitive medical matters should be dealt with “man to man and woman to woman”. Attention to physical cleanliness was highly important. Many were proud and self-reliant. Male family members were self-employed and this appeared to reflect their independent nature and tradition of economic adaptability. Stories told by research participants indicated that independence and pride were important cultural features influencing illness behaviour. Gypsy Travellers were reluctant patients. The women interviewed explained that many of the men were not registered with GPs even though they were settled on sites. The women themselves showed little doctor-dependency. One interviewee demonstrated a very stoical attitude in the face of significant pain and suffering.

(b) End of life care

There was a clear consensus of opinion with all interviewees that the last days of life were best spent at home in the care of the family. Talking about a man on site who had cancer:

“He was a handful, and they looked after him and they wouldn’t let him go... Yes, they looked after him and he died on here (the site)... They seem to think they are happier in their home, you know, they are more settled at home”
(Barbara)

This comment was accompanied by pride in the ability of her fellow Gypsy Travellers to provide personal care and avoid relinquishing the caring role during severe illness.

There was very little awareness of the existence or nature of hospices and when they were known about, although their potential use was not denied, the preference remained to spend the last few days at home. When Barbara was asked how families might respond if the doctor suggested a relative be admitted to a hospice. She replied

“They do go in, but like if they knows it’s their last days and that, they’ll have them home, you know.” (Barbara)

Jane and Debbie discussed the issue of conflict with hospital staff associated with large numbers of family members visiting sick relatives. They felt Gypsy Travellers prefer to care for dying relatives at home so that all the family could be together and avoid such conflict.

“I know my Aunt she solved the problem a bit because her husband was dying. She ended up bringing him home to die and that solved a lot of problems because his family was all at home then.” (Jane)

This preference for bringing one's relatives home to die is in stark contrast with earlier literature on the meaning and implications of avoiding ritual contamination in Gypsy Traveller culture which claimed that death is linked to pollution and that "ideally a Gypsy should die in hospital..."². This research however suggests that often Gypsies prefer to die at home.

(b) Cancer diagnosis disclosure

When asked about disclosure the participants expressed the view that loved ones with cancer should not be told of their diagnosis in order to protect them from distress.

"...They thinks if they don't tell them, it won't upset them so much..."

"They do keep it from them if they can possibly do it..." (Barbara)

Four interviewees expressed the view that disclosing the diagnosis of cancer can lead to shock, and shock can kill.

"But they shouldn't have told her because she was by herself... it could have killed her really couldn't it?" (Elizabeth)

Although strong opinions were expressed against direct disclosure to patients, the same respondents were quite clear that they themselves would like to be fully informed.

"I would like to face it by myself...I'd want to know, but not my family." (Sarah)

(b) Health Beliefs about cancer

During the interviews, health beliefs were discussed with particular reference to cancer. Three of the respondents described the nature of cancer in terms of the existence of two forms of cancer – a male cancer and a female cancer. The cancer as an entity was ascribed a gender description and not the organ which it affected.

"So what do you think about cancer. What is it?" (Interviewer)

"Well cancer is male and female. The female one lays eggs and so it spreads. It goes round the body. It's a bit like when a chicken lays eggs and sits on them. Then they hatch out. That's when it spreads and it kills you. Then the male cancer...just grows big strong roots that grow deep and that's what happened to my brother. It grew and grew and it got so big and strong it punctured his lungs and he died. But the female one, you can only freeze it for so long and then it spreads." (Sarah)

"So can women get male cancers?" (Interviewer)

"Of course!" (Sarah)

A second interviewee had a similar understanding

“There’s a woman cancer and there’s a man that’s a spreader.” (Elizabeth)

These beliefs also led on to an understanding of the effectiveness of various treatments.

“But there is a certain cancer once it’s touched (operated on), you can die with it... But if you don’t tamper with it, if you don’t put a knife to cancer it cannot bust or it can’t grow. I do believe in that and a lot of the Gypsy people believe not to touch a cancer” (Elizabeth)

Sarah also explained the view that operative intervention can expedite cancer progression.

“No. (If he had been operated on) The air would’ve got to it and he would’ve died” (Sarah).

In contrast, Barbara proposed an opposite opinion

“A Traveller will do anything ... they let them have operations...If they (the doctors) said they’d got a chance, they’d rather the operation.” (Barbara)

It is not possible to generalise these findings to the wider Gypsy Traveller population due to the small sample size and such beliefs may not be localised to the Gypsy population. However, the idea of male and female cancers has been found among other Gypsy Travellers (personal communication Patrice Van Cleemput 2005). LS has found many Gypsy Travellers have an understanding of cancer in terms of benign or malignant, local spread and metastases but they may find it easier to express themselves in story form.

(b) Health service experience

All the families encountered during the research were facing significant social problems, and for the Gypsy Travellers these often took priority over attention to their health. The major factor affecting access to health care was travelling around the country as opposed to being settled on a site.

“I went to the doctors to ask for the pill. Because I wasn’t in their area (they said) ‘we’re not giving it to you’ and a week later I fell for my son. I could have done with a break because I already had a little one year old.” (Jane)

“Yes when they (members of the health service) know you’ve settled down and it seems to be more alright then, you know.” (Barbara)

One participant described a series of difficult encounters with doctors but her own GP was held in high esteem, almost being seen as able to do no wrong. When interviewees were travelling away from their more permanent home, where they were registered with a

GP, there was reluctance to attend another GP as a temporary resident. Previous poor encounters with receptionists meant they would rather opt for attending Accident and Emergency departments.

“Do you know it was the way they used to treat us...like (the receptionist said) “you’re only a comer and a goer... I’ve got my patients”. It’s like we were nobody....I know if the babies were sick or anything I’d go straight to an hospital because I says to myself if I go to a doctor’s, they’ll say either “how long are you staying for” and err “who’s your doctor” and they give you so much aggravation.” (Elizabeth)

These findings concur with those of Parry and Van Cleemput ⁷.

The Gypsy Travellers interviewed had experience of failing to receive follow-up health care. Sometimes illiteracy prevented the Traveller being aware of notification about a forthcoming appointment. One participant suggested that if all health-related correspondence was on NHS headed paper it would be easier for them to recognise it and then arrange for it to be read. It was clear from fieldwork that the prime method of communication for many Travellers was the mobile ‘phone.

The e-group discussed difficulty with health care access but also commented that Gypsy Travellers themselves may at times distance themselves from health care. They suggested that there may be many reasons for this, but significantly there has been an historical mistrust of authority figures and non-Gypsy folk in general among Gypsy Travellers.

Gypsy Travellers often discharge themselves from hospital care very early. Some suggested that this may be related to “bricks and mortar” syndrome: Gypsy Travellers may have an aversion to being in a contained environment. They thought this may be a concept unfamiliar to medical staff. One participant suggested that offering the Gypsy Traveller patient a bed near a window may help.

The conflict that can arise with a hospital when a Gypsy patient has a large number of relatives was discussed at interview and in the e-group

“...The hospitals...don’t cater for...Traveller families. They have big families. My Mum comes from a family of fourteen” (Jane)

The Gypsies felt such situations could be handled more tactfully or sensitively, and made suggestions such as negotiating the use of a day room for the visit.

The e-group described how elderly patients may feel threatened as they may be unable to read and write and are sometimes reluctant to admit to this. Inability to fill out forms, e.g. menus can add to feelings of being a “fish out of water”. The e-group also commented that distress may be caused if the patient is unable to follow their usual hygiene practices. Issues mentioned included, food being served on the same table that is used for washbowls and bed pans and the difficulty of hand washing when confined to the bed.

(a) Discussion

Romany Gypsies are an ethnic group with cultural beliefs and practices that influence their experience of illness and health care including terminal illness. Their independence, stoicism and the closeness of their families contribute to their ability to care for their own in the terminal stages of illness. Their needs include support for caring at home, sensitive sharing of information and health professionals that respect their priorities and practices.

Mobility is an important part of the Gypsy Traveller culture and the Gypsy Travellers themselves recognise the impact this has on access to health care. The historical suspicion of the authority figure held by many Gypsy Travellers can make provision of services for this community difficult but this is being compounded by the current UK law resulting in increased enforced mobility. The lack of control over their mobility contributes to poor health and poor access to health services in addition to its indirect effects for health through availability of work and access to education¹⁵⁻¹⁷. However, they had suggestions as to how they and their health services could accommodate each other.

English Romany Gypsy Travellers have preserved their cultural distinctiveness while adapting to the changes in UK community life. Few want to give-up their Traveller identity. Although distinct, there is diversity within their community, something all research participants commented on, emphasising that they did not wish to speak on behalf of others. Their distinctive culture influenced the experience of terminal illness, as is found with all cultural groups¹⁸.

This study focused on one Traveller ethnic group, as the aim was to gain in-depth understanding of a sensitive topic. Gypsy Travellers themselves warned against assuming similarity of experience for other Traveller groups. The study participants all lived on authorised sites so our data is likely to underestimate the impact of mobility on access to health care. Travellers are not group easy to access for research purposes. Observation and interviews were possible only after time had been invested in building trust. This limited the size and scope of this study. The participants knew EJ was a doctor and this may have influenced the data collection. However, EJ was introduced as a friend of the community worker which is likely to have reduced the impact. The use of the e-mail forum enabled open discussion of subjects that would have been culturally difficult to explore face-to-face. The Gypsy Travellers in the forum were politically active but also engaged with their communities.

The research team addressed ethical considerations of internet research¹⁹. The study received ethical approval.

This paper demonstrates the need for sensitivity for Gypsy Traveller culture in the provision of palliative care. Future developments such as the electronic medical record may improve access to medical records for mobile patients. Reform of the law and policy in relation to Traveller sites is also essential for improving access to health care.

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Ethics

The research as conducted followed the 2002 Statement of Ethical Practice of the British Sociological Association available at www.britisoc.co.uk. The research team prepared written and audio information for participants and consent forms. However, participants found this formality difficult. EJ explained the research to all participants and was open about her research role to all the Gypsy Travellers with whom she came into contact.

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Appendix 1

Table 1

Table showing interviewees age-group and locality

Pseudonym	Age group (years)	Locality of interview
Sarah	80-90	Gloucestershire
Barbara	50-60	Gloucestershire
Elizabeth	40-50	Gloucestershire
Debbie*	20-25	Lincolnshire
Jane*	25-30	Lincolnshire
Kirsty*	15-20	Lincolnshire

*simultaneous interview