

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

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Aim: To understand the experience of terminal care 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 and seven semistructured interviews with Gypsy Traveller women who had experience of caring for relatives who were dying. In addition, data were collected over two years through discussion in a 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 by health care professionals and due to 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.

Key words: ethnicity; Gypsy; healthcare access; palliative care; terminal illness; Traveller

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*Len Smith died on the 16th December 2007 aged 68 years, having devoted his life to promoting Gypsy and Traveller rights. As well as co-founding the European Committee on Romani Emancipation, he was a founder member of the Traveller Law Reform Coalition and a co-founder of the National Federation of Romani Gypsy and Traveller Liaison Groups. In 2005, Len was the winner of Liberty and the Law Reform Society's award for Human Rights and in 2006 he won the Yellow Rose Award for the promotion of Human Rights. He was a frequent contributor to local and national press on Gypsy issues and was an advisor to government bodies on Gypsy and Traveller issues. Len came from a Gypsy background and lived most of his life as a wheelwright and carriage builder. His book, *Romany Nevi-Wesh – an informal history of the New Forest Gypsies* was published in 2004. He leaves his wife, Linda, their six children and 19 grandchildren.

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Background

According to written records, Gypsy Travellers have been resident in the UK since the 15th century and maybe even earlier (Thomson, 2003). 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 care (Linthwaite, 1983; Pahl and Vaile, 1988; Edwards and Watt, 1997; Van Cleemput, 2000; Van Cleemput and Parry, 2001;

Parry *et al.*, 2004). Gypsy Travellers are not included in the national census (Office of National Statistics, 2005) or the Health Survey for England (Department of Health, 2003). 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 intentions (Parry *et al.*, 2004). Many general practitioners (GPs) are reluctant to accept Gypsy Traveller patients as they perceive them as having poor health and as 'expensive' patients who fail to keep appointments and are poorly compliant (Friends Families and Travellers' Support Group, 1998).

In the UK, a review of health and health care for Gypsy Travellers demonstrated the need for improvement of their access to health services (Feder, 1989). Both public and charitable health care provision in the UK give considerable priority to palliative care (Macmillan Cancer Relief, 2003) and recognise the need to provide services appropriate to the needs of ethnic minorities (Hill and Penso, 1995; Gatrad *et al.*, 2003). However the particular needs of Travellers are not fully considered. The research set out to understand the experience of terminal illness for English Gypsy Travellers in order to inform palliative care provision for this and other Traveller groups. This required developing an understanding of their wider health and health care experiences.

Gypsy Travellers and accommodation

The impact of accommodation issues on the life and health of Gypsy Travellers was all pervasive in the research data. A contemporaneous survey of the health status of Gypsy Travellers in England also found it to be an 'overriding factor' in relation to health effects (Parry *et al.*, 2004). A series of recent reports highlight accommodation as the most prominent problem facing Gypsy Travellers and this has major impacts on health (Pahl and Vaile, 1988; Edwards and Prior, 1997; Hawes, 1997; Morris and Clements, 2001; Niner, 2003; Parry *et al.*, 2004). In 2003, the need for 1000–2000 additional residential pitches, and 2000–2500 further transit pitches throughout the UK over a five-year period was identified (Niner, 2003). In 2001, 24.2% of caravans were on unauthorised sites (Niner, 2003). Conditions on unauthorised sites can be hazardous to

health as they commonly lack basic amenities such as water, sanitation and refuse collection (Pahl and Vaile, 1988). Many authorised and unauthorised sites are situated on old waste tips and near motorways (Van Cleemput, 2000; Niner, 2003). One of the main field sites for this research was situated under a major grouping of power transmission lines.

In 1994, the Criminal Justice and Public Order Act was introduced. This has been described as criminalisation of travelling (Hawes and Perez, 1995). Responsibilities of local authorities to provide sites were removed and the police were given greater powers to evict families unlawfully camped. The lack of control over their mobility contributes to poor health and poor access to health services in addition to its indirect effects on health through availability of work and access to education (Parry *et al.*, 2004).

Methods

This study was undertaken with English Romany Gypsy Travellers in 2003–2004 and included a literature review, observational fieldwork, semi-structured interviews and online discussion. There are a number of distinct travelling groups in the UK including English, Welsh and Scottish Gypsies, Irish Travellers and new Travellers, each with their own identity. English Romany Gypsies were already known to EJ, therefore the research focused on an in-depth understanding of this group.

Access

Accessing participants was challenging as Gypsy Travellers are a marginalised group, and terminal illness and death is a sensitive subject. Data collection focused on the experience of terminal illness as related by family/community members. No attempt was made to recruit individuals in the terminal stage of illness. The literature on Gypsy Travellers indicated strict gender-defined boundaries, and as the author undertaking the fieldwork was female (EJ), only women Gypsy Travellers were interviewed on this sensitive issue, thereby respecting Gypsy Travellers' cultural norms (Okely, 1983). This was confirmed during the study in the on-line discussion. Access to interview participants developed over a period of 9 months involving approximately 20 days of researcher time with

many unproductive contacts. To reduce the impact that EJ's role as a doctor may have on the data, access was sought through non-health care channels. A lay person working with Gypsy Traveller families on creative art projects introduced EJ to Gypsy Traveller women. When considerable understanding of Gypsy culture had been gained, a further successful contact was made following a chance encounter with Gypsy Travellers in the community. All participants lived on authorised council sites for Travellers.

For two years, EJ joined an e-mail forum for Gypsy and Traveller issues. 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.

Interviews

The researcher (EJ) established a relationship with each participant before initiating interviews. Many informal visits were made to the participants and their families and EJ accompanied some participants on day trips including a trip to a Gypsy horse fair. The success of the interviews was reliant on commitment to these relationships based on trust and acceptance. 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 seven of these agreed to be interviewed. Two declined a formal interview although were happy to engage informally. Contact was lost with one woman when she moved on. All those interviewed were currently living on authorised sites.

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.

English Romany Gypsy Travellers display a distinctive use of the English language often using Romani words, especially for a non-Gypsy audience. During the research, time spent with Gypsy families allowed mutual understanding to develop.

The semistructured interviews started with identifying the women's experience of terminal care. EJ encouraged the women to give an account of this experience. The interview then explored related issues including disclosure of cancer diagnosis, access to health care and other experiences of health care. The interviews also explored the impact of mobility and accommodation issues on their experiences. The interviews were very informal, often interrupted by the coming and going of children, and lasted 45–75 min. The interviews were conducted in the trailer (caravan) or shed (utility building) of the interviewee and all but one were audio-recorded.

Observation

During the process of gaining access to participants and developing relationships with interviewees, field-notes were kept. These observations informed the development of the research process and were analysed along with the other data. Approximately 20 researcher days were spent with Gypsy Travellers collecting data, in addition to the time spent on access.

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 fieldwork, 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

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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)

Analysis

Data were read by the whole team and discussed at analysis meetings. Themes were identified by all team members. EJ coded the data on paper and concurrently drew a map of how themes were linked. This process continued for all the data, then the data analysed at the start of the process were reviewed. Finally the themes and mapping was reviewed by the whole team. When drawing a conclusion, the data were checked for confirming and disconfirming examples.

The results presented in this paper focus on the issues arising in the data that are most immediately pertinent to the experience of terminal illness for Gypsy Travellers including cultural issues, end of life care, cancer diagnosis disclosure, health beliefs

about cancer and health service experiences. However, these aspects of their experience need to be understood against the backdrop of their mobility and accommodation issues along with low levels of literacy, which itself is linked with these issues.

Study aims

The study aimed to understand the experience of terminal care and health care access for Gypsy Travellers, to inform palliative and primary care service provision.

Results

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 groups (Helman, 1984). However, the mobility of the Gypsy Travellers has an impact on their experience of terminal illness and death, which is not experienced by the vast majority of the UK-settled community. The Gypsy Travellers were aware of the impact their mobility has on issues such as access to health care services, and that historically Gypsy Travellers have tended to mistrust authority figures and non-Gypsy folk. However, they had suggestions as to how they and their health services could accommodate each other.

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. Gypsy Traveller culture places great emphasis on propriety of conduct. There were clear gender-defined boundaries for roles within the family. Attention to physical cleanliness was very important, with many being proud and self-reliant. The men were often self-employed and this appeared to reflect their independent nature and tradition of economic adaptability. Independence and pride was an

important cultural feature influencing illness behaviour, a finding confirmed in a recent health survey (Parry *et al.*, 2004). Gypsy Travellers appear to be 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 very little doctor-dependency. One interviewee demonstrated a very stoical attitude in the face of significant pain and suffering.

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. 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'. For example, a female forum member explained that even to use the word 'pregnant' was frowned upon in mixed company, 'expecting' being more appropriate if the subject could not be avoided. During visits to the Gypsy Traveller women, the topic of conversation was often changed abruptly when a man came into the trailer or shed.

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.

The Travellers always keeps them home... looks after them at home...I can't remember any of them sending them away.

(Barbara)

Barbara backed this up by telling of 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 seems 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 carer role during severe illness.

None of the participants had experience of palliative care services. 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...' (Linthwaite, 1983). This research, however, suggests that Gypsies prefer to die at home.

Cancer diagnosis disclosure

The issue of disclosure was explored with each interviewee and revealed a variety of views and experiences, although overall the view that predominated was 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)

In four separate interviews, with no prompting from the interviewer, interviewees expressed the view that disclosing the diagnosis of cancer can lead to shock, and shock can kill.

She's fragile and the shock might've killed her.
(Sarah)

I reckon ... it killed some of them with shock, when they told them.
(Barbara)

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

...The shock could have killed him...
(Jane)

Barbara felt that a diagnosis of cancer should be kept from certain individuals if their family deemed them vulnerable. She understood that often the patient would be informed directly by the doctor.

...Some of the Travellers, when they've found out, they wants err some of them not to know, and some to know... But mostly now, they (the patient) asks themselves, and the doctor will tell them 'cause that's a new law come out that they got to tell them.
(Barbara)

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.

Yes, I would, I would. I'd want to know.
(Barbara)

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

Barbara recalled a friend who had cancer being angry with her daughters for keeping her diagnosis from her.

...She was thinking she was getting treated for something...and the doctor told her straight, it was cancer, and then she went storm mad at her daughters cause they wouldn't tell her.... I reckon myself that if there's anything's wrong like that, you'd want to know to make plans and things.
(Barbara)

Health beliefs about cancer

During the interviews, health beliefs were discussed with particular reference to cancer.

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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 (Patrice Van Cleemput, 2005, personal communication). 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.

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. One 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)

Once trust had been established, the doctor was valued and held in high esteem, almost being seen as able to do no wrong. This was also found in other Traveller health research (Parry *et al.*, 2004). 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 A&E 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 say 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)

This finding concurs with that of Parry *et al.* (2004). The Gypsy Travellers interviewed had experience of failing to receive follow-up health care. Sometimes poor literacy 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 and get it read. It was clear from observation that the prime method of communication for many Travellers was the mobile phone.

The e-group discussed difficulty with health care access and also commented that Gypsy Travellers themselves may distance themselves from health care at times. They suggested that there may be many reasons for this, but significantly there has been a 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)

A lot of Gypsies talk different. They sound a lot louder.

(Debbie)

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 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 wash-bowls and bedpans and the difficulty of hand washing when confined to the bed.

Discussion

English 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 who 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 on health through availability of work and access to education (Edwards and Prior, 1997; Hawes, 1997; Morris and Clements, 2001). 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 groups (Helman, 1984).

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. As the study participants all lived on authorised sites, our data are likely to underestimate the impact of mobility on access to health care. Travellers are not an easy group to access for research. Observation and interviews were possible only when time had been spent on 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. Several participants seemed to appreciate the opportunity to talk about their bereavements during the process of relationship building. Although the interviews did not focus on bereavement issues, the data were influenced by their bereavement experiences. 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 and also engaged with their communities.

The research team addressed ethical considerations of internet research (Eysenbach, 2003). The study received ethical approval.

Palliative care services emphasise the provision of physical, psychological, social and spiritual care for the dying and their families (World Health Organization (WHO), 2002; Macmillan Cancer Relief, 2003). Research has highlighted the importance of services that are sensitive to the culture of Black and minority ethnic groups not including Gypsy Travellers (Hill and Penso, 1995). This paper demonstrates the need for such sensitivity for Gypsy Travellers.

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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