



## “It's because it's cancer, not because you're a Traveller”-exploring lay understanding of cancer in English Romany Gypsy and Irish Traveller communities

Jenni Berlin<sup>a,\*</sup>, David Smith<sup>b</sup>, Paul Newton<sup>c</sup>

<sup>a</sup> Researcher at the Faculty of Social Sciences, University of Tampere, Arvo Ylpönkatu 34, PL 100, 33014 Tampere, Finland

<sup>b</sup> Principal Lecturer in Sociology, Department of Psychology, Social Work and Counselling University of Greenwich, Southwood Site, Avery Hill Road, Eltham, London SE9 2UG, England

<sup>c</sup> Research Lead in the Department of Adult Nursing and Paramedic Science, University of Greenwich, Southwood Site, Avery Hill Road, Eltham, London SE9 2UG, England



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### ABSTRACT

**Purpose:** The lay understanding of cancer among English Romany Gypsies and Irish Travellers, has not been studied in depth before. Lay understandings of cancer, and illness in general, varies between different ethnic groups suggesting that procedures that work for one community may not work for another. Therefore, the measures that are in place in the UK to educate and treat people with cancer may not work for the - often hard to reach - Gypsy and Traveller communities. This study explores Gypsies and Travellers lay perceptions of cancer. **Method:** In collaboration with community interviewers, 18 Gypsies and Travellers were recruited to take part in this study. Data comes from four semi-structured focus groups that were transcribed and thematically analysed using data-driven coding.

**Results:** A lack of trust of the wider society has contributed to some Gypsies and Travellers' health related practices as has the persistence of old customs that negatively influence their health. As a reticence towards seeking outside help often exists, information about cancer is sought from family members. When engaged with cancer services however, Gypsies and Travellers generally feel them to be non-discriminative.

**Conclusions:** Health professionals need to develop a better understanding of Gypsy and Travellers' health beliefs and practices in order to successfully interact with them. Information about cancer has to be delivered in an understandable form and to places where it reaches these communities. Because of historical societal discrimination, including by some health services, engaging with Gypsies and Travellers may require considerably more time and effort.

### 1. Introduction

Research indicates that knowledge of lay understandings of health and illness is important when designing effective and appropriate health care and support services for different communities. Different ethnic groups have their own systems of beliefs, perceptions and ideas about health and illness that influences the experiences of illness and health seeking behaviour (e.g. Helman, 2007; Dein, 2004.) In fact, it has been argued that “understanding cultural responses to cancer are as important to healthcare professionals as knowledge of statistical trends” (Dein, 2004:119).

Lay understandings of illness are based on personal experience of what happens or has happened to the individual, their family and/or closest friends (Prior, 2008:179). Hearsay and word-to-mouth have

been recognised as an important source of health information among Gypsy and Traveller communities (Ipsos MORI, 2009). A number of studies have highlighted a taboo surrounding discussion of cancer in those communities with many community members associating cancer diagnosis with certain death (Parry et al., 2004; Van Cleemput et al., 2007). Parry et al. (2004) also found that there is a consensus that family members with cancer should not be told that they had the illness. In terms of lay understanding, Jesper et al. (2008) found that some Gypsies and Travellers described the nature of cancer not in relation to the physiological body but as a distinctly gendered disease, particularly in terms of who may be prone to it. Other studies identify a belief that the disease is contagious (Twiselton and Huntington, 2009), -while others report a belief that discussing cancer can make one more susceptible to it (Ruston and Smith, 2013). Some Gypsies and Travellers

\* Corresponding author.

E-mail address: [jenni.berlin@uta.fi](mailto:jenni.berlin@uta.fi) (J. Berlin).

<sup>1</sup> Permanent Address: Flat 7173–177 Hornsey Road, N7 6RA London England.

also believe that a bad diagnosis from a health professional can actually harm the patient's overall resilience (Welsh Government, 2015).

While the above studies highlighted some of the lay beliefs and perceptions of cancer none of them focused specifically on either cancer, or on Gypsies and Travellers' lay understandings of cancer or health in general. Capturing lay understandings of health and illness are an important component of providing tailored health promotion, advice and communication training for health care professionals, and therefore, this study explores Gypsy and Traveller communities lay understandings of cancer.

## 2. Methods

This article presents the findings of exploratory focus group research which used a critical constructivist approach (Crossley, 2005) to look into English Romany Gypsies and Irish Travellers' lay perceptions of cancer. The research takes the stance that much of our reality, and the categories and frames we use to explain and interpret everyday life, are socially constructed, and that human knowledge is constantly being constructed by the surrounding cultures, structures and people (Crossley, 2005). As Gypsies and Travellers can be considered as extremely close-knit and segregated communities suspicious of the outside world and its institutions (Berlin, 2015), we argue that their perceptions of cancer are mainly (although not exclusively) constructed by their own social norms, culture and people. This exploratory study increases knowledge of these segregated communities and their perceptions of, and practices surrounding cancer.

The research was conducted by organising four focus group interviews. These were conducted in 2016 with adult members (18 + years) of English Romany Gypsy and Irish Traveller communities in two locations one in the South East and the other in the East of England. 18 participants took part (two men, 16 women). Thirteen of the interviewees were English Gypsies and five were Irish Travellers, see Table 1.

As Gypsies and Travellers can be considered as extremely 'hard to reach' communities, the participants were recruited with the help of community interviewers known to the researchers. All participants were given a Participant Information Sheet prior to interview, and were asked to sign a Consent Form if they decided to take part. The interviews were audio recorded with participants' permission, and transcribed verbatim using a professional transcribing company.

To explore lay perceptions of cancer within Gypsy and Traveller communities, a semi-structured topic guide was designed to gather information about issues identified from previous research and the literature review, see Table 2. Probing questions were used to gather more information on issues the participants brought up themselves. This assured that the participants' perspectives and concerns about the research topic were not overlooked. Using a data-driven approach of thematic analysis and treating the four focus groups as subsamples, we identified and then compared themes within the focus groups and between them (Boyatzis, 1998: 41). This led to the creation of five codes, the main themes of our research, which will be introduced in the results. The identified themes were discussed and agreed upon with the research team and community interviewers.

This article introduces the findings by using illustrative quotations from the focus groups. The focus groups are coded with numbers 1–4.

**Table 1**  
Focus groups.

Focus group 1	Focus group 2	Focus group 3	Focus group 4
3 English Gypsy women	3 English Gypsy women	4 English Gypsy women	1 English Gypsy woman
1 English Gypsy man	1 English Gypsy man		5 Irish Traveller women

**Table 2**  
Topic guide for focus groups

<p>Topic 1: Explore your experiences beliefs and practices surrounding cancer.</p> <ul style="list-style-type: none"> <li>• Health workers and researchers who work with Gypsies and Travellers often say it's hard to get them to discuss cancer – is this true in your experience and if so why?</li> <li>• What do you consider to be the major causes of cancer?</li> <li>• Where does your knowledge and information about the disease come from? (E.g. public health information, media, friends/family).</li> <li>• Do you feel you have enough (or too much) information about the disease?</li> <li>• Should someone diagnosed with cancer be told about it? If so why/why not?</li> <li>• How would someone be treated if they were diagnosed with cancer (E.g. would people feel uncomfortable/avoid/visit/offer help/care)?</li> </ul> <p>Topic 2: Investigate the experiences of yourself and/or your family members surrounding palliative and end of life care in formal healthcare settings.</p> <ul style="list-style-type: none"> <li>• If anybody had a loved one/friend become ill with cancer how do you consider the quality of treatment they received from healthcare/medical staff – was it appropriate to their needs?</li> <li>• How do you consider the attitudes of healthcare and medical staff towards (the sick person/your relative/friend) and their level of understanding towards people from Gypsy and Traveller backgrounds?</li> <li>• In your experience, how did the medical/nursing staff relate to the family and visitors who came to the hospital/hospice?</li> </ul> <p>Topic 3: Examine any unmet needs or obstacles in relation to effective cancer care that you/your family or friends may have experienced.</p> <ul style="list-style-type: none"> <li>• Were there any aspects of care or of their time in hospital which could have been better?</li> <li>• Do you consider there were aspects of your culture and the way you treat cancer that the doctors and nurses didn't understand?</li> </ul> <p>Topic 4: Consider how cancer care could be organised to better suit the needs of you and other Gypsies and Travellers.</p> <ul style="list-style-type: none"> <li>• How could cancer services be improved so they better met the needs of Gypsies and Travellers?</li> <li>• What training on this issue would benefit medical staff? What would you want them to know/understand?</li> </ul>
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'(F)' means that the respondent is female and '(M)' that they are male, e.g. '(F3)' is a female participant from focus group 3. When displaying parts of discussion, the interviewer is marked with '(Int)'.

## 3. Results

This chapter analyses the following five themes that were identified from the data:

- Gypsies' and Travellers' beliefs about cancer
- Fear and stigma surrounding cancer
- The role of gender and gender based care for those with cancer.
- How Gypsies and Travellers look for and would like to receive information about cancer
- Perceptions and experiences of cancer treatment and medical professionals

### 3.1. Gypsies' and Travellers' beliefs about cancer

Many Gypsies and Travellers will not talk about cancer because they see this as invoking bad luck; as bringing forth painful memories of family members who have suffered or died from the disease and as causing their families too much worry. Because of a widely held belief among Travellers that there is no cure for cancer, it might be ignored entirely, with people carrying on with their lives as normal: 'I think that's because they'll never find a cure for it, all the research and that they do, they're never going to find a cure for it and I think that's why it's so, people don't like to talk about it because there's hundreds and hundreds of different types of cancer and they haven't found a cure for any one of them yet ... ' (F3).

Cancer was referred to by our interviewees as 'that old cover', 'that old thing', 'that disease', 'the C word', or 'the bad complaint': 'What my daughter will say is, "that old cover" or "that disease", I think I try not to say the word "cancer" but at some point, I'm forced to and part of that is because my mother dying of it, I think it's almost for me, it's like it brings back her to

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