

RESEARCH REPORT

Health-related beliefs and experiences of Gypsies and Travellers: a qualitative study

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Worldwide there are more than 100 groups of Gypsies and Travellers who collectively form part of a wider Romani population, estimated at 12 million people. The Gypsies and Travellers in this study comprise English and Welsh Gypsies, Irish Travellers and Scottish Gypsy Travellers. English and Welsh Gypsies and Irish Travellers form an estimated population of 500 000 in England and Wales.^{1–3} Nomadism and caravan (trailer) dwelling, although not defining them, are features of their cultural heritage rather than a lifestyle choice; many live in houses and others live on authorised or non-authorised residential caravan sites.⁴ They are among the UK's most socially excluded groups⁵ despite legal protection as a result of their ethnic minority status.

There are many previous studies of health meanings, values and practices among different cultural groups, and studies concerning beliefs and views about specific health problems. However, there seems to be little information concerning general views and perceptions of health and influences on the health of Gypsies and Travellers.

This was not a comparative or theoretically informed study, but a descriptive qualitative strand of an applied policy mixed methods study designed to estimate the current health status of Gypsies and Travellers. The key finding from the health status survey was the high burden of ill health among Gypsies and Travellers.⁶ We designed the qualitative study using a framework approach⁷ to put their health status into context by purposively selecting a sample to explore how ill health was experienced and understood by this minority group.

There are few previous qualitative studies on the health of Gypsies or Travellers in the UK and Ireland,^{8,9} and most report anecdotal data from practitioner accounts.^{10–12}

Objective: To illuminate findings of the survey of the health status of Gypsies and Travellers by exploring their health-related beliefs and experiences.

Design: Qualitative study of a purposive subsample from in-depth interviews using framework analysis.

Setting: The homes or alternative community settings of the participants in five geographically dispersed study locations in England.

Participants: 27 Gypsies and Travellers with an experience of ill health, purposively sampled from a larger population participating in an epidemiological survey of health status.

Results: The experience of poor health and daily encounters of ill health among extended family members were normalised and accepted. Four major themes emerged relating to health beliefs and the effect of lifestyle on health for these respondents: the travelling way; low expectations of health; self-reliance and staying in control; fatalism and fear of death. These themes dominated accounts of health experience and were relevant to the experience. These themes add richness to the health status data and inform our understanding.

Conclusions: Among Gypsies and Travellers, coherent cultural beliefs and attitudes underpin health-related behaviour, and health experiences must be understood in this context. In this group, ill health is seen as normal, an inevitable consequence of adverse social experiences, and is stoically and fatalistically accepted. The provision of effective healthcare and improvement of poor health in Gypsies and Travellers will require multi-agency awareness of these issues.

METHODS

Participants and setting

The sampling frame comprised 269 Gypsies and Travellers participating in a parallel study of their health status conducted at five English locations: the survey sample was itself constructed to include quotas of men and women, Irish and British, across roadside, official, private and housed accommodation. Within this frame, anyone who reported a recent or current health problem and therefore had cause to access health services was eligible for inclusion in the qualitative study (ie, intensity sampling). Maximum variation purposive sampling¹³ was also used across the study localities to ensure a representative final sample (table 1). A variety of health problems or unidentified symptoms were reported among the final sample (appendix A). Interviews were distributed over a 12-month period to capture any seasonal variation in mood and health states.

Research governance approval (including multicentre research ethics committee ethical review) was obtained with secondary approval from primary care trusts and local research ethics committees in each location where health visitors worked.

Interviews

Data were collected by individual in-depth semistructured interviews with participants in their own homes or at a venue of their choice. The interviews were carried out within 2–3 weeks of completion of the Health Survey Questionnaire. A topic guide was developed from five sources: personal practitioner experience; previous pilot study¹⁴; other published evidence; advice from the project advisory team, which included Gypsy Travellers; and initial pilot interviews. Non-directive interview questions allowed the exploration of

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