Health status of Gypsy Travellers
Patrice Van Cleemput and Glenys Parry

Abstract

Background Although previous studies suggest that Gypsy Travellers have poorer health status and excess mortality compared with the general population, there is no epidemiological evidence using validated measures in this nomadic ethnic group. The aim of this study was to compare the health status of traditional Gypsy Travellers with norms from the UK population, and with a concurrent comparison group using the Euroqol health status measure (EQ-5D).

Methods Eighty-seven adult Gypsy Travellers were matched for age and sex with English or Irish residents, registered with an urban general practice in an area of high social deprivation. Both samples completed the EQ-5D questionnaire by interview. A comparison was also made with normative data from the UK general population.

Results Travellers had poorer health status than their settled counterparts on two of the five dimensions (mobility and activity) but not on the overall summary score. Travellers reported significantly poorer health than the matched comparison group on the EQ-5D visual analogue scale. Both the Travellers and the comparison group had much poorer health status on the EQ-5D index than the UK population norms, even when compared with the lowest socio-economic group.

Conclusions Health status of Gypsy Travellers was significantly poorer than in the lowest socio-economic UK population group, but was not so markedly different from a concurrent, matched, socially deprived resident group. Gypsy Travellers did have poorer health status than matched comparators in relation to mobility, activity and perception of overall health. Quantitative assessment of health status in the Traveller community is feasible.

Keywords: Gypsy Travellers, health status, Euroqol-5D, inequality

Background

In the British Isles Gypsy Travellers mainly comprise English and Welsh Romanichal or Romany Gypsies, Irish Travellers and Scottish Travellers, plus a growing number of European Romanichals (Roma). They each have their own language, beliefs and cultural heritage, but they share a strong traditional culture and a mistrust of the settled population. Gypsy Travellers are not defined by travelling and living in caravans but by their ethnicity. In 1989, the English Court of Appeal made a legal ruling that Romanies were an ethnic group, in a case brought by the Commission for Racial Equality (CRE v Dutton). The ruling took into account the “Mandla criteria” for an ethnic minority (i.e. sharing a common history, culture, oral literature and practices of a religious nature).

Although nomadism is part of their heritage, many Gypsy Travellers live all or part of the time in houses. This is often due to the unavailability of places on authorized sites or the extreme difficulties associated with the travelling lifestyle. Nomadism as a state of mind and not simply a lifestyle is described by McDonagh: “for Travellers the physical fact of moving is just one aspect of a nomadic mind set that permeates every aspect of our lives. Nomadism entails a different way of looking at the world, a different way of perceiving things.” Gypsy Travellers are, arguably, the most socially excluded group in society. Botes et al. in their submission to Sir Donald Acheson’s enquiry into inequalities in health described Travellers as a ‘hard to reach’ group because their circumstances exclude them from accessing routine health care provision.

Estimating the numbers of Travellers is difficult because of their nomadic lifestyle. Routine morbidity data in health authorities for this ethnic group are not available because, with no separate ethnic coding, they would be usually classified as white Caucasian rather than separately identified as an ethnic minority. It is easy for agencies to ignore their needs with such fragmentary information on health status. Limited existing research on Travellers’ health mainly concentrates on maternal and child health. It suggests that the health status of traditional Gypsy Travellers is well below the national average, with a higher rate of childhood accidents, higher proportion of babies of low birthweight and higher death rates from cardiovascular disease. Professionals working with Travellers report high morbidity from their experience, but we could find no basic epidemiological data using a validated health status measure. The current study reports the health status of Gypsy Travellers on such a measure, compared with a resident group who may be expected to share many of the same forms of social exclusion or deprivation, and compared with UK normative data.

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Epidemiological research into ethnicity and health has been criticized for making global comparisons between ethnic groups in ways that at best make unwarranted assumptions about the relationship between ethnic group membership and health, and at worst make a series of basic errors. In an attempt to avoid this, we have followed the recommendations of Senior and Bhopal to improve the value of ethnicity as an epidemiological variable. Specifically, we state explicitly the definitions used for our ethnic group sample, we carefully chose a concurrent comparison group to explore the important confounding variable of socio-economic disadvantage, as a possible explanation of differences in health between ethnic groups. Rather than simply measure health inequalities between groups, which can itself contribute to social disadvantage, we designed the study to be of maximum use to health service planners and health policy makers in reducing the impact of social exclusion and improving access to health services to disadvantaged groups.

Method

Study population

The study population was drawn from Gypsy Travellers aged 17 years and above living in Sheffield during the study period November 1998–April 1999 inclusive. The Traveller population in any location is by definition a fluctuating one, but there is a core of the study population that spends a high percentage of their lives using Sheffield as their main town. On average, between 100 and 150 Gypsy Traveller adults are living in Sheffield and known to the specialist Travellers’ Health Visitor at any given time. Over a 3 month period the Health Visitor estimated movement in and out of Sheffield of between 30 and 40 adults in the winter and between 40 and 60 adults in the summer, including Travellers moving out and returning within the time period. Between 40 and 60 Travellers are estimated to move into Sheffield in the course of a year for the first time. The Sheffield population usually comprises approximately 60 per cent English or Welsh Gypsies and 40 per cent Irish Travellers. Most of the English or Welsh population is found on authorized caravan sites and most of the Irish population in houses, especially in the winter months. The demography of Sheffield’s Gypsy Traveller population is not necessarily replicated in other areas.

Because of the nomadic nature of the subjects and fluctuating numbers within the sampling frame, random sampling was not feasible. Instead, all available Travellers were approached, irrespective of demographic background or type of accommodation. By inviting all possible Travellers to participate we aimed to limit selection bias. To have an 80 per cent power of detecting a 15 point difference in mean EQ-5D utility scores as statistically significant at the 5 per cent (two-tailed) level, we required 73 (Traveller comparison) pairs. We originally expected to approach approximately 120 adult Travellers to form the subject sample, of whom we assumed 75 per cent would agree to participate.

The specialist Health Visitor spoke to the Travellers about the proposed study, in the course of her normal work, to allay fears or suspicion of the motives of the researcher. Non-Travellers visiting Gypsy Traveller dwellings are usually viewed with great suspicion and therefore it was important that someone who had already gained trust facilitated the introduction of the researcher. The Health Visitor taught the researcher about the history and culture of Gypsy Travellers so that he would not inadvertently offend anyone through ignorance of their beliefs and way of life. During this initial 2 week period the researcher also accompanied the Health Visitor on her routine visits, to familiarize himself and for many of the Gypsy Travellers to meet him before the start of the study. The Health Visitor provided regular updated lists of adult Travellers currently in Sheffield and advised about optimum times to attempt contact. After Local Research Ethics approval was granted, the interviewer met Traveller and comparison subjects in their homes and read the explanatory leaflet to them before obtaining informed consent.

All measures were completed by interview because of known poor literacy levels. [In 1995, a survey by one of the authors (P.V.C.), found that fewer than 30 per cent of Travellers in Sheffield could read or write at all.] The only section of the questionnaire that was completed by the respondents, after an explanation by the interviewer, was the visual analogue scale.

Comparison group

Approximately 50 per cent of the Traveller population in Sheffield attend a particular General Practice. This urban practice is in an area of high socio-economic deprivation, having a Townsend deprivation score (1991) of 5.1 (best –8.4; worst 6.4; 92nd out of 99 practices in Sheffield) and a Jarman score (1997) of 25.7 (range 0–90.3; 64th out of 99 practices in Sheffield).

Given the difficulty of assigning socio-economic status to Gypsy Travellers, it was decided to draw a comparison group from indigenous white English and Irish local residents registered with this practice and matched for age and sex with each interviewed Traveller. We selected the comparison group to be the closest possible counterparts to the Gypsy Travellers, who were from both English and Irish backgrounds. The comparison group therefore comprised English and Irish residents in a socially deprived neighbourhood.

For each successful interview with a Traveller subject, three possible matched comparison subjects were drawn from the surgery’s register. They were contacted by post, with a letter from their general practitioner (GP) explaining the reason for a request for the interviewer to visit them in their homes. We had also placed an explanatory poster in the surgery waiting room. We interviewed the first of each matched subject that responded. Interviews with the comparison subjects took place during the same time scale as those with the Traveller subjects and the identical method was used, regardless of likely higher literacy levels in the comparison group.
Health status measurement

The EQ-5D is a brief generic health status or health-related quality of life measure, designed by health economists for health utility research. It has been used in national health surveys in England, from which age–sex norms have been established for the general population. Comparative data are also available for different population sub-groups. The EQ-5D defines health in terms of five dimensions: mobility (physical ability to walk), self-care, usual activity (work, housework, study, family or leisure), pain or discomfort, and anxiety or depression. Each dimension is scored at one of three levels (no problem, some problem, or extreme problem). Each possible combination of levels from each dimension yields a total of 243 health states, which are scored on a tariff derived from general population utility valuation. The questionnaire also includes the respondent’s own perception of their overall health by use of a visual analogue scale designed to resemble a thermometer.

Extra information

Additional information, including age, sex, smoking habit, employment status, education level and postcode, is included on the final page of the three-page questionnaire. We excluded the background question on employment status because we expected some reluctance to answer this question. We added questions on Gypsy Traveller national origin (i.e. English, Welsh, Irish), accommodation type (e.g. council site, roadside site, housed), travelling patterns, and GP registration status.

We were concerned that the item on ‘anxiety’ and ‘depression’ would be difficult for Travellers to answer, as these terms are not used in their culture. As the EQ-5D is a standardized measure, the wording cannot be altered, so we used an additional item translated into the more colloquial terms ‘nerves’ and ‘feeling fed up’ and compared the responses to the same question with different wording.

Results

Eighty-seven Gypsy Travellers agreed to participate. Response rates were 86.7 per cent for the Traveller group and 91.1 per cent for the comparison group. The age and sex distributions were matched in each. The mean age range was 37 (16.1) with range of 17–77 years. Fifty-five were female (63.2 per cent) and 32 were male (36.8 per cent).

On the weighted health state index there was a significant difference between the UK population and both the Traveller group ($t = -4.775, p < 0.001$) and urban deprived group ($t = -3.369, p < 0.001$), but the difference between the Travellers and their matched comparison group was not significant ($t = -1.84, p = 0.7, ns$) (Table 1).

The proportions of individuals reporting any problem were similar in the Travellers and urban deprived group, but were significantly greater for Travellers than for lowest UK socio-economic groups and the UK general population ($\chi^2 = 17.32, p < 0.0001$).

The EQ visual analogue scale showed a significant difference between the Travellers and urban deprived group ($t = -2.009, p < 0.05$) as well as highly significant differences between Travellers and UK unskilled manual group ($t = -5.961, p < 0.001$), and Travellers and UK general population ($t = -6.782, p < 0.001$).

The five dimensions of the EQ-5D are given separately for the two study groups compared with UK norms (Table 2). A

<table>
<thead>
<tr>
<th>Table 1</th>
<th>EQ-5D summary scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Travellers</td>
</tr>
<tr>
<td></td>
<td>($n = 87$)</td>
</tr>
<tr>
<td>EQ index, mean (SD)</td>
<td>0.65 (0.396)</td>
</tr>
<tr>
<td>Any problem (%)</td>
<td>65.5</td>
</tr>
<tr>
<td>Visual analogue scale</td>
<td>61.9 (28.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2</th>
<th>EQ-5D dimensions: proportion reporting any problem (numbers, with percentages given in parentheses)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Travellers</td>
</tr>
<tr>
<td>Mobility (all ages)</td>
<td>37/87 (42.5)</td>
</tr>
<tr>
<td>Self care (all ages)</td>
<td>9/87 (10.3)</td>
</tr>
<tr>
<td>Usual activities (all ages)</td>
<td>37/86 (43.0)</td>
</tr>
<tr>
<td>Pain or discomfort (all ages)</td>
<td>34/87 (39.1)</td>
</tr>
<tr>
<td>Anxiety or depression (all ages)</td>
<td>31/86 (36.0)</td>
</tr>
</tbody>
</table>
significantly greater proportion of Travellers reported problems with mobility ($\chi^2 = 5.77, p < 0.05$) and usual activity ($\chi^2 = 5.02, p < 0.05$) compared with the urban deprived residents. Compared with the UK general population, a significantly greater proportion of Travellers reported problems on all dimensions, except pain and discomfort, where the difference was not significant.

The comparison between Travellers and the matched urban deprived group was repeated using their colloquial wording for the item on anxiety or depression. It was found that the proportion of Travellers reporting any problems with ‘nerves’ and ‘feeling fed up’ was significantly greater than the matched comparisons (35 per cent versus 19 per cent, $\chi^2 = 5.84, p < 0.05$). Using this wording, the EQ-5D index score was also significantly worse for Travellers than their resident counterparts (0.63 versus 0.76, $t = -2.306, p < 0.02$).

The proportion of Travellers who were smokers was not significantly different from the urban deprived residents (57 per cent vs 47 per cent, $\chi^2 = 1.306, ns$). In both groups, smoking was related to poorer health status ($t = -2.45, p < 0.05$).

The linear regression model estimated that age and smoking are significant independent predictors of EQ-5D score, but being a Traveller and gender are not significant independent predictors.

There is a significant negative correlation between age and EQ-5D. There were similar findings in the age relationship in the UK population, with the rate of reported problems increasing significantly with age (Tables 3 and 4).

Frequency of travel was the independent variable that had a significant influence on both the EQ-5D index score and the visual analogue score. The Travellers who travelled more frequently had better EQ-5D and visual analogue scores ($t = -2.87, p < 0.005$ and $t = -4.17, p = 0.0001$).

### Discussion

The response rates show that data collection of this type is feasible in Gypsy Traveller populations, but this did require frequent return visits (up to 11) to a high proportion of respondents. With this method, we show it is possible to achieve high response rates on a standardized health measure, although we believe this would not have been possible without the role of the Health Visitor as trusted intermediary.

The preponderance of women in the sample raises questions about its representativeness. Fewer men than women were available for interview, either because they were out working in the day, or possibly making themselves inaccessible even if they did not outwardly refuse to participate.

#### Table 3 Travellers only: influence of independent variables on EQ-5D score

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta coefficient</th>
<th>95% CI</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel frequency</td>
<td>-0.13</td>
<td>-0.22 to -0.04</td>
<td>-2.87</td>
<td>&lt;0.005</td>
</tr>
<tr>
<td>Smoking</td>
<td>-0.27</td>
<td>-0.46 to -0.08</td>
<td>-2.82</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Age</td>
<td>-0.006</td>
<td>-0.01 to -0.001</td>
<td>-2.40</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Living (caravan or house)</td>
<td>0.08</td>
<td>-0.12 to 0.27</td>
<td>0.78</td>
<td>0.44</td>
</tr>
<tr>
<td>School leaving age</td>
<td>-0.002</td>
<td>-0.02 to 0.01</td>
<td>-0.32</td>
<td>0.75</td>
</tr>
<tr>
<td>Traveller type</td>
<td>-0.03</td>
<td>-0.21 to 0.15</td>
<td>-0.28</td>
<td>0.78</td>
</tr>
<tr>
<td>Sex</td>
<td>-0.02</td>
<td>-0.18 to 0.15</td>
<td>-0.19</td>
<td>0.85</td>
</tr>
</tbody>
</table>

$r^2 = 0.216$, constant = 1.44 [95 per cent confidence interval (CI) 1.03–1.85]. Dependent variable is EQ-5D score. Independent variables entered into model: age (interval); sex (binomial: 0, male; 1, female); smoking (binomial: 0, never or ex smoker; 1, current smoker); school leaving age (interval); Traveller type (binomial: 0, English or Welsh; 1, Irish or Scottish); living (binomial: 0, caravan; 1, house); travel frequency (ordinal: 1, all year; 2, in the summer; 3, rarely travel; 4, never travel).

#### Table 4 Travellers only: influence of independent variables on visual analogue score

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta coefficient</th>
<th>95% CI</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel frequency</td>
<td>-12.71</td>
<td>-18.79 to -6.64</td>
<td>-4.17</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Smoking</td>
<td>-18.74</td>
<td>-31.60 to -5.87</td>
<td>-2.90</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Age</td>
<td>-0.40</td>
<td>-0.76 to -0.04</td>
<td>-2.24</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Living (caravan or house)</td>
<td>7.92</td>
<td>-5.64 to 21.49</td>
<td>1.16</td>
<td>0.25</td>
</tr>
<tr>
<td>Sex</td>
<td>-7.15</td>
<td>-18.29 to 3.99</td>
<td>-1.28</td>
<td>0.20</td>
</tr>
<tr>
<td>Traveller type</td>
<td>-1.01</td>
<td>-13.44 to 11.42</td>
<td>-0.16</td>
<td>0.87</td>
</tr>
<tr>
<td>School leaving age</td>
<td>-0.07</td>
<td>-1.05 to 0.90</td>
<td>-0.15</td>
<td>0.88</td>
</tr>
</tbody>
</table>

$r^2 = 0.285$, constant = 137.2 [95 per cent CI 99.4–154.9]. Dependent variable is visual analogue score. Independent variables entered into model: age (interval); sex (binomial: 0, male; 1, female); smoking (binomial: 0, never or ex smoker; 1, current smoker); school leaving age (interval); Traveller type (binomial: 0, English or Welsh; 1, Irish or Scottish); living (binomial: 0, caravan; 1, house); travel frequency (ordinal: 1, all year; 2, in the summer; 3, rarely travel; 4, never travel).
Comparisons are most robust and most conservative between the Travellers and the matched urban deprived residents. Although there was no difference in the overall EQ index score, the sub-scores and visual analogue scale showed that the Traveller’s health status is poorer in terms of mobility and usual activity and perceived overall health problems. These differences cannot be attributed to age, sex or generic social deprivation, and show the health impact of membership of this socially distinct ethnic minority group.

The cultural validity of the EQ-5D item about anxiety or depression may be problematic, in that these terms are not used in the Traveller community. Our concerns seemed to be justified by the analysis using a colloquial version, which revealed significant differences between Travellers and the urban deprived residents, suggesting that the wording of this item is culturally sensitive. The difference was such that the EQ-5D score would have been significantly lower for the Travellers had the colloquial terms been used. However, there would need to be a revalidation of the whole measure, using the cultural wording, for this finding to be valid.

The comparisons with UK norms are less robust because a different method of data collection was used (personal interview versus self-completed questionnaire). However, the differences found were of an order of magnitude that is hard to attribute to methodological variance. The Travellers’ health status is poor, even when compared with the lowest UK socio-economic groups.

The effects of age on health status seem to be similar in the Traveller group and the comparison groups, in that older people report more health problems, although the effect is more marked for Travellers. However, there are fewer older adults in our sample to make meaningful age comparisons. Smoking is related to health status in Travellers as with other groups, and it is a significant independent predictor of the EQ-5D score.

The association between the frequency of travel and both EQ-5D scores and visual analogue scale ratings may have two explanations. Those in poorer health may be less able to travel. Conversely, or in addition, this could indicate that inability to lead their cultural nomadic lifestyle, for whatever reason, has a negative impact on Gypsy Travellers’ health. The difficulties that Gypsy Travellers now have in trying to live their cultural nomadic lifestyle have increased since the introduction of the Criminal Justice and Public Order Act in 1994,13 which not only made parking caravans for even short periods on the roadside a criminal offence, but also repealed the Caravan Sites Act of 196814 with its duty to provide sites. Councils therefore no longer need to build sites, and they can also close existing sites. The significance of nomadism as a central feature of Gypsy Traveller culture has already been mentioned. Qualitative research focusing on health concerns suggested that forced changes to travelling patterns and the related impact on lifestyle may have a detrimental effect on quality of life and mental health.15 Ginnetty, in this qualitative study of Travellers’ perspectives on health, observed that ‘the meaning of living in a house is linked to a range of emotions from isolation, loneliness, loss of identity to feeling “closed in”’. On the other hand, one might expect a negative impact on health of the lack of basic amenities on Travellers stopping on unauthorized sites, and the lack of a permanent address, which would further reduce access to health and related services.

This study has demonstrated the feasibility of using the EQ-5D as a validated measure with the Gypsy Traveller community, despite some culturally inappropriate wording. It appears that the Sheffield Gypsy Travellers have poorer health as well as being a ‘hard to reach’ group. Although this finding needs to be replicated in a national study, it poses a question for policymakers and health authorities on how to address the health needs of a minority ethnic group who, despite moving in family groups, are often excluded from health provision and health improvement plans.

Current health policy places particular emphasis on reducing inequalities in health and targeting socially excluded groups16,17 although, ironically, a key policy document in this regard, Reducing health inequalities: an action report,18 does not address the health needs of Gypsy Travellers, perhaps demonstrating the extent of their social exclusion.

In addition to health inequalities, there are good reasons to believe that Gypsy Travellers have unequal access to health services. Feder19 gave evidence of large numbers of GPs who will not accept Travellers onto their practice lists, causing them difficulty in reaching ‘sympathetic’ GPs. A recent Health Select Committee report on provision of NHS mental health services suggests that ‘the vulnerability of minority populations to inappropriate services is arguably greater when they represent a tiny proportion of the local population’.20

Planning guidance emphasizes Fair Access for such socially excluded groups and it is likely that there are a number of health interventions, many quite simple and cost effective, that Travellers need but do not receive. The findings reported here suggest that the factors affecting equity of access to health services are complex and interacting. They include Gypsy Traveller cultural attitudes, ethnic minority group membership and socioeconomic disadvantage. However, the effects of these global socio-demographic factors are mediated through specific circumstances. For example, Morris and Clements21 showed that Gypsy Travellers continue to face appalling conditions on some authorized sites and that not all Gypsy Travellers are provided with the basic amenities when parked on unofficial sites. Hawes’ pointed out that nomadic Gypsy Travellers place greater priority on the practicalities of finding safe and well-serviced stopping places, sanitation and water supply than on medical issues such as immunizations and cervical smears.

For these reasons, planning fair access at the Health Authority level will require culturally appropriate health services for this group, including mental health services, in close liaison with local authorities, through health and social care partnership arrangements.
Acknowledgements

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1 CRE v Dutton (1989) 1 All ER 306.

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