

Traveller gypsies and primary care

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SUMMARY. Traveller gypsies have resided in the British Isles for over 500 years, making them one of our oldest ethnic minorities. They experience widespread prejudice and discrimination from the settled population. In the sphere of health care the marginalization of traveller gypsies has resulted in poor access to services and relative neglect of their health needs. In this paper the health of traveller gypsies is reviewed from the perspective of primary care, and the role of general practitioners in improving health care for this community is discussed.

Introduction

THE first record of gypsy groups in the UK dates from the early sixteenth century and their origin is still the subject of ethnographic debate.^{1,2} There are four distinct traveller gypsy groups in the UK,³ but they are geneologically and linguistically related:

<i>Group</i>	<i>Language</i>
North Welsh Kale	Inflected dialect of Romanes
South Welsh and English Romanichals	Creolized dialect of Romanes
Irish Pavees or Minceirs	Gammer which mixes middle Irish backslang (Shelta) with English and Romanes
Scottish travellers	Cant which combines creolized Romanes and Gammar vocabulary

The travelling gypsy population has always been heterogeneous, changing as the result of migration and interchange with settled communities. The longstanding myth of the true or pure gypsy as distinct from other traveller groups is fallacious, but useful to local authorities who want an excuse not to provide services to encamped traveller gypsies.⁴

The caravan site act of 1968 used a broad definition for traveller gypsies: 'Persons of nomadic habit of life whatever their race or origin', but this ignores their cultural distinctiveness. Wibberley⁵ coined a more specific definition after wide consultation (including traveller organizations) when he reviewed the working of the caravan site act:

'Nomadic families who by reason of their lifestyle habitual travel to sell the products of their self employment and to pick up casual or seasonal work, and whose only or main residence is a caravan or tent for which they have no permanent site.'

There are approximately 10 000 gypsy caravans in the UK and, assuming a minimum of three children per family, at least 50 000 traveller gypsies. Although Wibberley's definition may be appropriate for planning caravan sites, it is still inadequate for defining the whole traveller community. Oakley argues that the traveller identity derives from lineal descent reinforced by specific cultural choices.¹ This definition includes the approximately

48 000 gypsies who live in houses but still share traveller cultural values and, to some extent, languages. The total population of travellers in the UK is thus approximately 100 000, clustered mainly in East Anglia, Kent, Wales, Scotland, London and urban areas in the Midlands.

Although traveller gypsies identify themselves as a distinct ethnic group, this is not yet universally recognized. For example, a judicial ruling in June 1987 that a landlord was not contravening the race relations act by displaying a 'No travellers' sign was only overturned in the court of appeal in July 1988.⁶ Traveller gypsies are now protected under the race relations act and can take legal action if discrimination occurs.⁷ The failure to acknowledge traveller gypsies as an ethnic minority is also obvious in accounts of multi-cultural health care, where they are completely ignored.⁸

Why is the definition of 'traveller gypsies' important for health care providers? First, research on traveller gypsies' health and planning of services requires criteria for defining the traveller population. Secondly, recognition of traveller gypsies as an ethnic group may lead to better understanding of their perception of health, illness, prevention, and the role of health services.

Health of traveller gypsies

Although there are approximately one million gypsies in western Europe, 2.5 million in eastern Europe and 500 000 in the USA, there is a dearth of research into their health status.

In the UK there is no national mortality data for gypsies because 'traveller gypsy' is not an occupational category, nor has there been a prospective morbidity study, which would be difficult to organize in such a mobile population. All that exists are anecdotal reports from doctors or health visitors working with travellers, a few small studies of specific health problems and two retrospective studies of child and maternal health. These accounts suggest higher morbidity rates and earlier mortality than among the settled population.

Maternal and perinatal health

One of the earliest reports of serious perinatal problems came from a general practitioner and health visitor in Sheffield who set up a travellers' health project. They recorded a cluster of six perinatal deaths out of 12 births to traveller women between January and August 1982 (Heller T, Peck B, unpublished report).

Systematic data on maternal and child health were first collected in an East Anglian study sponsored by the Save the Children Fund⁹ in which 265 traveller mothers were interviewed about their obstetric history, children's health and use of health services. A perinatal mortality rate of 142.4 per 1000 births, a stillbirth rate of 113.9 per 1000 and an infant mortality rate of 53.6 per 1000 were reported. The report was heavily criticized on methodological and political grounds.¹⁰ It was also criticized by traveller groups for stigmatizing their community as a 'special case' with an unhealthy lifestyle and poor motivation to use health facilities. However, the study led to an excellent conference¹¹ where many of the issues of traveller gypsies' health were clarified.

In a study in Kent by Pahl and Vaile,¹² 263 traveller women were interviewed. The sample included a high proportion of the target population but there was a problem of data reliability, since there was no way to verify the information obtained by self reporting. The perinatal mortality rate was found to be 16 per 1000 births, the stillbirth rate 12 per 1000 and the infant mortality rate 17.5 per 1000. Although considerably lower than the

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rates found in East Anglia, these results are still worse than regional and national rates, with the stillbirth rate showing the greatest difference (national rate 7.2 per 1000). Pahl and Vaile maintain that a detailed perinatal audit is necessary to explain the difference between the rates in East Anglia and Kent. Such a study would also help explain the difference between the rates in both studies and in the settled population.

Pahl and Vaile found a higher proportion of low birthweight babies (less than 2500 g) among Kentish travellers than nationally (12.8% compared with 6.9%). They also found that stillbirth and infant death rates were higher for mothers on private and unauthorized sites than on local authority sites. Another clue to the higher mortality rates is a correlation with increased mobility, which is particularly worrying in the light of a report by the Association of Metropolitan Authorities (unpublished, 1988) showing that 16 authorities would evict pregnant women from unauthorized sites and 13 would evict women close to birth.

Child health

The age structure of the traveller gypsy population throughout Europe differs from the settled population in that approximately 50% of travellers are under 16 years of age.³ Large families are the norm; in Sheffield in 1982 28% of travellers had more than six children (Wilson G, unpublished report, 1987). In traveller culture child care has a high priority, not only among women, but unfortunately poor environmental conditions and difficult access to health care lead to a relatively high child morbidity.

In 1979 Sampson and Stockford¹³ observed a low level of immunization among traveller children and an increased rate of polio and less serious infectious diseases, as well as an increased accident rate. Pahl and Vaile's study in Kent showed that 11% of under five year olds suffered from serious injuries, most commonly lacerations, scalds and burns.¹² Their data on serious illness is difficult to interpret because uniform criteria were not used for judging the severity of illness episodes. The Kent study also included immunization rates, and a comparison with the rates found by Linthwaite in East Anglia⁹ and a study in Walsall¹⁴ is shown in Table 1. Pahl and Vaile point out that epidemics of infectious diseases have not been reported among traveller gypsies despite the low immunization rates. They speculate whether this is due to poor reporting of episodes — unlikely in the case of polio, diphtheria and tetanus — or to the relative isolation of traveller communities. A Scottish study suggests an alternative explanation (Riding M, MSc thesis, University of Glasgow, 1985). In a sample of 109 travellers aged five to 61 years the immunization rate was low: 56.0% had no recollection of any immunizations. However, 83.5% had antibodies to polio, 81.0% to diphtheria and 50.5% to tetanus (about equal to the settled population, although traveller occupations, such as farmwork and scrap metal dealing, put them at greater risk of tetanus). The study also picked up a high exposure rate to hepatitis A. A curious aspect of this study is the conclusion that 'the general population should not be apprehensive about the development of well run permanent sites in their locality'.¹⁶ This reflects society's generally negative and fearful perception of travellers. As Hussey points out, studies of nomads worldwide often take as a premise the potential risk of infection to the settled community (Hussey RM, MSc thesis, University of Manchester, 1987).

Although the Scottish study gives some reassurance about the consequences of a low immunization rate, this is still an important issue in the health care of travellers, especially as the level of immunity in the UK traveller population as a whole may not be as high as in Scotland. There are anecdotal reports of an increased pertussis and measles morbidity among traveller children (Dodge L, personal communication).

Table 1. Number of traveller children vaccinated by end of second year as a percentage of total born compared with figures for all children in England.

	Percentage completion of vaccinations			
	Polio	Diphtheria/ tetanus	Pertussis	Measles
Kent ^a	24	24	10	14
Walsall ^b	20	20	5	12
East Anglia ^c	7	9	0	12
England (1984) ^d	84	84	65	62

^aRef 12. ^bRef 14. ^cRef 9. ^dRef 15.

In Ireland, a prospective study of 108 traveller children aged between two and 13 years showed a consistent height deficit compared with children from the settled community.¹⁷ However, no conclusion about environmental or genetic contributions can be drawn, especially as parental height was not measured. A retrospective Irish study showed decreased head circumference in the first year of life in traveller children admitted to hospital compared with non-traveller children, although the study was flawed by the absence of a hospital based control group.¹⁸ There is no comparable data from the UK, but these studies are relevant to traveller child health care in this country because of the relatively large influx of Irish traveller gypsies over the last 20 years.

Another cause for concern is evidence for an increased risk of autosomal recessive disorders among traveller children because of intermarriage and a high consanguinity coefficient. In a study of 1200 traveller gypsies in south Wales, Williams and Harper found a phenylketonuria incidence of one per 40 compared with a one per 6000 in the settled population.¹⁹

Among accounts of traveller child health there are a number of optimistic signs. In the Walsall study,¹⁴ where environmental and physical risk factors were increased for traveller children compared with other children, there was a lower incidence of non-accidental injury among travellers. In Roehampton, after an unvaccinated traveller baby developed polio, travellers welcomed an immunization initiative by the local department of community medicine. With the help of a Romany Guild spokesman, a 92% uptake of oral polio vaccine was achieved.²⁰

Adult health

There is evidence from Walsall¹⁴ and Sheffield (Wilson G, unpublished report, 1987) that premature death from cardiovascular disease is more prevalent among traveller gypsies than in the surrounding population, even when this is predominantly working class. Traveller health projects have also noticed widespread smoking among adults.²¹ Heller and Peck noted a high incidence of respiratory tract infection, along with chronic skin conditions and ear, nose, throat and eye problems (unpublished report, 1983); although they do not state the prevalence of each condition or analyse their age distribution.

Although there is no reliable adult morbidity data for traveller gypsies in the UK, a recent study of 58 American gypsies showed high rates of hypertension (78%), diabetes (48%), peripheral vascular disease (39%), renal impairment (20%), smoking (86%) and obesity (84%).²² The authors also noted 14 deaths at a mean age of 48 years. The study has severe limitations, as the sample was not randomly selected. Nevertheless, even if there was a large selection bias, the findings are disturbing. Thomas and colleagues found a high degree of consanguinity, and postulated an important role for heredity in the prevalence of cardiovascular disease in this community.²² Until prevalence studies are carried out in the UK, we cannot know if these results

are relevant to traveller gypsies in this country. Certainly American gypsies are directly related to European traveller gypsies, most arriving in the USA in the late nineteenth and twentieth centuries, and aspects of their lifestyle and culture²³ are similar to those of British travellers.

A hostile environment

Although some of the studies cited above suggest a hereditary component in the raised morbidity of traveller gypsies, there is consensus among all those concerned with travellers' health — not least travellers themselves — that the main explanation lies in adverse environmental conditions and poverty. Nationally there are not enough permanent sites or resting places for travellers.

This situation has not significantly improved since the introduction of the caravan sites act in 1968, by which local authorities are required to provide specified numbers of authorized sites. There are not enough sites and 3000–4000 caravans are encamped on illegal sites with poor or no facilities, liable to eviction at short notice by police or bailiffs.⁵

Unfortunately, even when a traveller family is on an official local authority site, there is no guarantee of a safe environment. A study carried out by Kent housing officers in 1984 showed six sites on former refuse tips or adjacent to active tips (unpublished report). Pahl and Vaile¹² found that basic amenities were absent on many sites, including official ones, and the provision of basic amenities in East Anglia⁹ was equally poor if not worse (Table 2). In Kent about a third of sites have a poor level of cleanliness and safety. Sixty per cent of traveller mothers reported problems in caring for their children because of:

'dirt, fast traffic, rats, lack of safe play areas, difficulty drying clothes, overcrowding, mud, dogs, broken glass, the site getting "used up" with toilet holes, lack of education, noises from factories, smells from nearby sewage works...'¹²

Table 2. Percentage of traveller families without basic amenities on sites in Kent¹² and East Anglia.⁹

	Percentage of families without amenity				
	Water	Elec- tricity	Toilets	Rubbish collection	Postal delivery
Kent (n = 125)	14	21	33	25	32
East Anglia (n = 123)	30	— ^a	58	— ^a	35

n = total number of families. ^aNo data available.

In addition there are other potential hazards which parents may not be aware of. In 1980 a survey of the Westway gypsy caravan site in west London demonstrated dangerous airborne and soil lead levels.¹¹ Despite this report, the site remains open. Conditions on many traveller sites are comparable to shanty towns in the developing world. Even a World Health Organization target for 1990 that everyone should have access to safe drinking water will not be reached for travellers in the UK. Women travellers are increasingly 'trailer-bound' and an increased proportion of men are dependent on social security.²¹ As in the wider world, there is a polarization between the relatively well off and the poor. This growth of poverty among traveller gypsies has a detrimental effect on health.

The main obstacle to the provision of adequate sites for the travelling community is local opposition.²⁴ Applications for planning permission for private or local authority sites are fiercely contested. Travellers are therefore forced to camp illegally with no facilities and the resulting state of the site confirms the negative image of travellers held by local people.

A consideration of environmental conditions needs to go beyond the physical environment. Gypsies have always been a persecuted minority in Europe. For more than two centuries, until 1783, gypsies were excluded from the UK and on discovery were punished with the death penalty. More recently gypsies were actively exterminated in Nazi Europe.²⁵ Although this extreme form of oppression no longer exists, traveller gypsies are still physically attacked,²⁶ besieged²⁷ and shot at.²⁸ This hostility from the surrounding community and the constant threat of sudden eviction when illegally encamped must have a detrimental effect on mental and physical health,²⁹ aside from its damaging effect on the continuity of health care.¹³

Although perceived by the settled population as outsiders and intruders, many contested urban and rural areas where travellers camp have been traditional stopping places for more than a century.³⁰ Throughout this time travellers have occupied a marginal but valuable economic niche.²

Access to health care

Health care is not necessarily a major determinant of health status, but

'inequality in the availability and use of health services in relation to need is in itself socially unjust and requires alleviation.'³¹

All the evidence suggests that poor access to primary health care is a major problem for travellers. However, there are several innovative traveller health projects which seek to rectify this problem.^{14,32}

There is general agreement in the literature that many general practitioners do not accept traveller gypsies as patients.³³⁻³⁵ Linthwaite, in a postal questionnaire to general practitioners in East Anglia found that 27 out of the 45 who responded did not accept travellers on their lists.⁹ This result is difficult to interpret because the sample was non-random and it is not clear whether the responding general practitioners would see the travellers as temporary residents. A survey of general practitioners in east London (97% response rate) showed that 10% of practices would not accept travellers at all.³⁶ As a consequence travellers may often travel great distances to attend general practitioners who are sympathetic. Pahl and Vaile found that 19% of their sample had a general practitioner more than five miles away, and 5% travelled more than 20 miles.¹²

General practitioners are not alone when it comes to turning traveller gypsies away. Health visitors dealing with travellers also report hostility towards travellers in antenatal and child health clinics.³⁷ Discrimination against travellers directly contravenes the race relations act, but even if all general practitioners and clinics welcomed travellers, there would remain other barriers to good health care arising from the mobility of travellers, different cultural perceptions of illness and time keeping, illiteracy, absence of postal services and absence of medical records.

To overcome these barriers and provide an acceptable level of health care, health authorities need to plan services and actively seek out traveller gypsies, especially those who are not on permanent sites. In an early analysis of health care for travellers, Sampson and Stockford¹³ wrote to all area health authorities (as they were then) for information on how they catered for the health care of traveller families; they found scant evidence of planning. Although a few area health authorities tried to plan services for traveller gypsies, initiated multi-disciplinary teams and even provided mobile health clinics, the majority did not recognize that there was a problem to be solved. Seven years later, in a questionnaire to directors of community nursing services, in all 191 English district health authorities (87% response), Hussey found that the situation had not improved.³⁸ Only 11

districts had any kind of outreach or special maternity facilities for travellers, although 50 had a designated person with responsibility for travellers' health care. Of the 158 districts with a general policy on prevention or health promotion, only five mentioned travellers.

Travellers' health visitors

Although the national picture of health care for traveller gypsies still looks bleak, there are a growing number of specialist health visitors and health projects concerned with the health of traveller gypsies'. While travellers' health visitors are sometimes part of a mobile team including a community medical officer,³³ they often work in relative isolation.³⁹ The nursing literature contains vivid accounts of their work, although there has been little evaluation of effectiveness. The approach of these workers was initially an adaptation of the traditional health visitor role, focusing on preventive health care of young children with an agenda of health education for mothers.³² This was often not successful. Peck writes:

'I sometimes feel that I have lost my way as a health visitor, as the last thing a young gypsy mother wants to hear about is preventive medicine or health education. She wants help getting the smashed window replaced in her trailer and sufficient money to buy food for her family and do her washing at the launderette. Above all, she would like a stopping place for the trailer, without fear of harassment from the local residents or local authority.'⁴⁰

The most interesting development in traveller health care is the adoption of a patient centred approach,^{14,41,42} starting from travellers' concerns and problems. This considerably broadens the role of the travellers' health visitor. He or she becomes an advocate who mediates between travellers and health professionals, as well as local authorities and social security officers.

There is a shift from providing 'special' health and preventive services directly to travellers, to helping them integrate into existing facilities. Liaison with and education of general practitioners is an important part of this work. In this light it is disappointing to find that in east London, where a travellers' health visitor has been in post since 1981, 10 out of 25 practices who had seen traveller patients over a one year period, did not know of the health visitor's existence.³⁶

The challenge to general practitioners

As general practitioners we do not have any direct influence on local site provision or the environmental conditions which undermine the health of our traveller patients. Nevertheless, we can publicly support demands for secure and safe caravan sites.

At the level of health authority policy making, general practitioners with traveller patients should request the appointment of a designated travellers' health visitor, if one does not already exist. Aside from his or her other roles the health visitor can help in the follow-up of traveller patients, particularly when literacy is a problem and postal services are absent.

A travellers' health visitor encourages general practitioners to move from a reactive position dealing only with acute health crises towards the provision of preventive health care for travellers. A travellers' health visitor can also help general practitioners negotiate some of the cultural differences between doctors and their traveller patients, who often have their own concepts of hygiene and illness.

Problems with continuity of care and lack of medical records in such a mobile population have prompted projects to introduce hand-held family health record cards in Sheffield, Kent, Walsall, east London and East Anglia. Although these cards have not yet been formally evaluated, initial enthusiasm has been dampen-

ed because many general practitioners are not aware of their existence and do not request them from their traveller patients.⁴³ In view of evidence for low immunization uptake, increased cardiovascular risk factors and perinatal problems, general practitioners should initiate opportunistic screening whenever travellers consult them.

Although general practitioners should aim to integrate traveller patients into the normal health care system, there will always be a need for 'outreach' work, particularly on temporary sites and with the more mobile travellers. Every health authority with a traveller population needs to coordinate this work, which will sometimes be undertaken by community medical officers and sometimes by general practitioners in conjunction with travellers' health visitors. Training for these professionals is essential if their intervention is to be successful. Any health or preventive initiative should be based on close consultation with the local traveller communities, who are best placed to identify specific problems.

Improving primary care for travellers is a challenge to our flexibility as general practitioners, and a real test of our ability to provide a non-judgemental, patient-centred service. Travellers are not the only group whose health needs require a specific response. The skills we acquire will strengthen our work with other groups who currently are not well served by the health service, such as other ethnic minorities⁴⁴ and the homeless.⁴⁵

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The following organizations are active in the field of travellers' health care:

Save the Children Fund, Mary Datchelor House, 17 Grove Lane, London SE5 8RT.

Acert, Mary Ward Centre, 42 Queen Square, London WC1 3AJ. Maternity Alliance, 15 Britannia Street, London WC1X 9JP.

National Gypsy Education Council, Templars Infant School, Crossing Road, Whitham, Essex.

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