

# **Travellers and End of Life Care**

## **1 Introduction**

In relation to Travellers, end of life care and palliative care, these are a number of areas which may be of some importance to the work of the committee. These include, the status of Travellers as a minority group within Irish population; socioeconomic deprivation within the Traveller population; lower levels of education, including literacy; shorter life expectancy, poorer health status, and different causes of morbidity and mortality; different cultural and ethical approaches to communication and interaction with health services, which will be addressed in this submission.

## **2 Travellers as a minority group**

Travellers are a minority within Irish society. They are recognised by the Government as a separate group and are specifically named in discrimination legislation (Employment Equality Act 1998, Equal Status Act, 2008.) The origin of Irish Travellers is not clear; there are suggestions that they are completely separate to the Irish population; other suggestions are that they are descended from dispossessed Irish who had been made landless during political conflicts. Travellers identify themselves and are identified by settled people as different to each other. Genetic studies suggest that the Traveller population is endogenous rather than as a result of migration e.g. of Roma into Ireland, but the population has become isolated over many years. (North et al, 2000, Murphy et al, 1999, Cavaleri, unpublished, personal communication). At different times in Irish society, the idea of Travellers not being a separate group has led to hostility at times from the settled population rather than the recognition of and respect toward difference.

There are approximately 36,000 Travellers in Ireland, representing less than 1.0% of the total population. A challenge for health care staff and services is in maintaining awareness, education and training for staff to deal with different groups whom they may encounter infrequently.

Travellers have traditionally had a number of well recognized disadvantages. These include poor education and poor literacy, and socioeconomic deprivation with high levels of unemployment and poverty; these factors are associated in all populations with poorer health outcomes.

The All Ireland Traveller Health Study, Our Geels, published in 2010 gathered general data, and health information. 75% of Travellers in the Republic of Ireland lived in family units of 5 or less; 73% lived in a house, 57 % of which was provided by a local authority; and 18% lived in trailer, mobile home or caravan. In the previous year, 78% of families had not travelled. 28% of families reported difficulty reading or filling out forms. Most (98%) are Catholic, and religion is rated as very important by 53%.

40% reported that they often or very often felt discriminated against. Travellers sometimes hid their identity so they could access things they believe may be denied to them if their ethnic origin was clear. This is called 'passing off' and parents reported that their children changed their accent or dress in certain situations to hide their identity.

Traveller societies can be considered collectivist rather than individualist. Collectivist societies value the needs of the family as much, if not more so than the needs of the individual. Families are interconnected and the immediate family can include extended family such as aunts, uncles and distant cousins. The strong emphasis on the importance of families attending for life rituals means that there are large family gatherings, which can cause anxiety for the settled population if for example hundreds of people arrive in a town for funerals, weddings or other family events. This can also cause problems in healthcare settings, as at times of serious illness large crowds can gather in hospitals to provide support for the patient.

### **3 Travellers, health and health service use**

The All Ireland Traveller Health Study showed that Travellers have a higher rate of doctor-diagnosed chronic health problems than the regular population, especially chronic bronchitis and asthma. (A similar, though much smaller study of the health of Gypsies and Travellers in England by Peters et al, shows that Gypsies and Travellers had poorer health than age and sex matched controls from deprived areas and ethnic minority populations. Respiratory illnesses were particularly prevalent; there were no differences between Gypsies and Travellers and the matched populations for cancer, stroke and diabetes.)

This study showed that Travellers had access to health services-for example most had a medical card. However, Travellers are less likely to have complete trust in health care professionals; 41% compared to 82.7% in the settled population. Travellers are more than twice as likely to use the Accident and Emergency Department as the settled population. Travellers are more likely to be admitted via the emergency room than electively (80%vs 35%), are less likely to have a discharge letter written (67% vs. 100%), were less likely to

have OPD follow up appointments (40% vs. 77%) or to be referred to clinical support services (21% vs. 62%) in comparison to the settled population. (Use of Hospital Facilities by the Traveller Community, 2004, Traveller Health Unit, Eastern Region).

Travellers have a higher Standardized Mortality Rate than the majority population. The SMR for the general population has improved in the last twenty years, as has the SMR for Traveller women, but the SMR for Traveller men has worsened.

The cause of excess mortality is reported as respiratory illnesses, followed by external causes such as accidents and suicides. Traveller male life expectancy, at 61 years has not improved since 1987, and is the same as the settled male population in 1945, and is 15 years shorter than the settled population. Female Traveller life-expectancy has improved since 1987, and is now 71 years, the same as the female settled population in 1960.

To quote directly from the All Ireland Traveller Health Study, 'Travellers experience a higher mortality than the general population. The problem is endemic and complex and will not be solved in the short term without considering the wider contextual issues. The picture points to the need for a holistic long term approach to improving the lives of Travellers and reducing their deaths...The fact that an identifiable disadvantaged group in our society is living with the mortality experience of previous generations 50-70 years ago cannot be ignored.

#### **4 Travellers and palliative care**

Research by Van Doorsaler and McQuillan, has shown that Travellers have little knowledge of hospice and palliative care. Travellers are fearful of discussing cancer. The word was avoided or when mentioned was accompanied by prayers or blessings. The belief expressed was that by discussing cancer especially or other serious illnesses, bad luck would befall the speakers. Speaking of serious illness and death was considered to invite these.

When a Traveller is seriously ill it is the custom from extended family and friends to visit and spend time supporting the patient and the immediate family. Travellers consider the habits of settled people, when only small numbers of people visit is not appropriate. Traveller custom can mean that large crowds (one hundred would not be unusual) would wish to visit especially as the patient is approaching death. Travellers are demonstrative and the combination of demonstrative behaviour and large crowds can lead to healthcare staff

feeling overwhelmed. Unless staff understand the importance of this behaviour, their response which can include restriction of visiting and calling security to manage visitors, can increase stress and distress. Identifying key people within the family and using clergy can facilitate Travellers visiting and the managing institutional concerns.

When a patient is dying families will often request a priest to attend for prayers and blessings. Healers may also be asked to visit the patient. Items of religious significance such as medals or relics may be placed around the patient and at times placed over the affected area of the body. Staff need to ensure they are not lost during medical and nursing care.

Hospitals are seen as places of hope, where cure is possible. Hospices are seen as a last resort, and although Travellers in Van Doorslaer's research who had experienced hospice care were positive about the experience, it was not an experience that was welcomed, being considered recognition and an acceptance of the terminal nature of an illness.

Travellers were more positive toward community palliative care, (hospice home care) as a way of providing additional help and support for the patient and family. Many respondents saw advantages to the person being cared for at home- surrounded by family, no restriction on visitors, and no disturbance to other patients. Care at home was not considered appropriate if the patient needs medical care which could not be provided at home or was too burdensome for the family. Death at home was usually considered unacceptable, whether the family lived in a house or a trailer. This is because of the feelings of great sadness associated with the death, which can mean that families find it hard to stay in a place where a death has occurred. Traditionally the trailer of a person who died, especially if the death happened in the trailer, would be burned. Families would move away from the site. This happens less frequently now, partly for economic reasons and also because most Travellers live in houses. More commonly now, families may try sell a trailer associated with someone who dies, but it can be difficult to find a buyer for a trailer in which a death has occurred. Travellers who live in houses may, following a death, move out of the house for a period of time, and not return until the house has been redecorated and blessed. For these reasons, families often do not want a family member to die at home.

Research carried out by the Parish of the Travelling People (Travellers Last Rights), found similar results. These included the fear of serious illness and of death, strong religious beliefs and expression, including the importance of religious rituals to support the sick, the centrality of the family and the importance of visiting the sick. Travellers also reported the importance of being present if something were to go wrong, that the sick person be

surrounded by 'their own' and that the sick person has the opportunity to pass on their last wishes.

## **5 Travellers, deaths funerals, memorialization and bereavement**

Funerals are usually organised by men in the Irish Traveller community. For many Irish Travellers having an elaborate coffin and headstone is considered a sign of love and respect. In recent years this has led to greater expense and families may go into debt to pay for a funeral. Traditionally, Travellers are buried in the burial ground associated with their family. Nowadays, especially as more travellers are settled rather than nomadic, Travellers may be buried where their family live. There can be tension in the family if there are different views between the family of origin and the family of marriage about the place of burial and attention and negotiation is needed. Given that many hundreds of people will attend funerals and that it is usual for there to be loud and demonstrative expression of grief, Traveller funerals can cause stress for the settled population. This can lead to intervention by the police which if not appropriately handled can increase tensions.

Traveller families usually have a month's mind, but different families may have other rituals which may include a blessing on the ninth day after the death, which is considered by some that that is the day the soul enters heaven, or the day the person is judged. For other families there may be monthly Masses for a year. Graves are visited on important personal dates such as birthdays or wedding anniversaries. The first anniversary, when the headstone is erected is sometimes called the Blessing of the Cross when what is considered the immediate family will gather; this can be three to four hundred people.

A number of studies, (Brack, Van Cleemput) emphasise the grief and sense of loss experienced when a member of the community dies. This can be so extreme among Irish Travellers as to cause the family to move away from the place of death or burn the trailer, as outlined above. The use of alcohol to cope with bereavement was recognised as not always being helpful (Van Doorsaler and McQuillan, Van Cleemput et al, Brack et al).

## **6 The dominant discourse-whose voice?**

Much is written in health care literature, including the palliative care literature about the importance of open communication and, leading from this, informed consent for treatment. Open acknowledgement and preparation for death is also promoted. These are important

principles that need to be tempered with respect for an individual's coping style and communication wishes. Research with Irish Travellers has shown that they consider disclosure of a diagnosis of a serious illness will cause a patient to give up hope. Travellers can find the communication styles of settled people, including healthcare staff unfeeling in its frankness.

Hope is extremely important in the face of serious illness, including hope for a cure, or a longer life. In the context of palliative care, hospices are avoided as they represent loss of hope, whereas hospitals are considered favourably as places which represent hope of cure. Religious and spiritual help is important to support patients.

Many members of the settled community also cope with serious, life-threatening illness by denial, avoidance and maintaining hope. This can be a useful coping strategy, but is not always sustainable. This coping strategy does make decision making about current and future care, including advance care planning, more challenging. Healthcare staff need to be able to recognize the coping strategy of Travellers (and others who cope in a similar way) and help them deal with serious illness while maintaining realistic hope. This can mean that strategies used in some countries, for example, routinely identifying patients as being in the last year of life, or asking patients about their preferred place of care, or place of death, may be inappropriate.

Travellers in common with many ethnic groups are part of a collectivist rather than individualist society, with a strong emphasis on family involvement. Ekblad's study of palliative care nurses views about caring for patients from different cultures showed that many culture clashes experienced by palliative care staff touched on the differences between group/family and individual orientated thinking.

Specialist palliative care, which emphasizes individual care and attention to detail, is in an ideal situation to address palliative care needs of ethnic minorities. This requires that specialist palliative care recognise the individuality of people, the role of the family and the ethical implications and difficulties of dealing with different viewpoints. Cultural awareness training is important and a balance between education about cultures and avoiding stereotyping is important. Patients from minority groups, including Irish Travellers subscribe to varying degrees to their own and the majority culture. Healthcare staff who are caring for people from other ethnic groups need to be aware that they may have different beliefs and rituals around serious illness, dying and death and have different experience of how societies work. Cultural mistrust may also impact on the way ethnic

minorities interact with palliative care services. This has been described in relation to the African American community and is also alluded to in this research; a common perceived barrier to accessing care is prejudice. Healthcare staff need to provide culturally appropriate care in so far as is possible, recognizing the importance of hope and the role of the family and different ideas about what constitutes a good death.

## **7 Recommendations**

7.1 To ensure that members of the travelling community die well in Ireland, must in the first instance, consider how to address high premature mortality of Travellers. There are a number of recommendations from the All Ireland Traveller Health Study including

- addressing the causes of respiratory and cardiac disease;
- efforts to improve trust between Travellers and the general population;
- staff training during induction for health services which have a significant Traveller catchment population, including guidelines on how to manage traveller families.

7.2 Accessible information for healthcare staff about caring for Travellers; for example, web-based education, or mobile apps. (These could build on the Intercultural Guide produced by the HSE Social Inclusion Unit, currently being developed as an app.) This may ensure that information is available when needed, rather than being delivered only as an undergraduate or postgraduate module.

7.3 Maintaining a focus the needs of the patient with life-threatening illness and their family, a palliative care approach, rather than focusing on prognosis and approaching death.

7.4 Adoption of the National Clinical Care Programme for Palliative Care clinical competencies, which include the importance of recognising cultural differences, communication skills, and ethics.

7.5 Ensure that any standards introduced to monitor health care delivery, including palliative care are capable of recognizing the needs of minorities, not just the majority culture.

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