



Home, hospice or hospital?

A study of Irish Travellers' use of
palliative care services

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In summary

Palliative care can dramatically improve the quality of life of people who are dying, and those who might need the service should be able to avail of it, whatever their ethnic or cultural background. Culture is important in the context of palliative care because it strongly influences our attitudes to death, dying and bereavement. Hence, palliative care services must be aware of and sensitive to cultural differences, and palliative care professionals must ask if the services they provide are inclusive of all ethnic groups in the area, or if they were designed, albeit unintentionally, with the dominant majority in mind. This appraisal is essential as Ireland becomes more ethnically diverse. It is also long overdue: Ireland has its own indigenous ethnic minority, the Travelling community, and anecdotal evidence suggests that Travellers make little use of palliative care services.

To identify the difficulties, real and perceived, that impact on contact between the Irish Travelling community and the specialist palliative care services, we held focus group discussions with Traveller women, and surveyed and interviewed professionals from palliative care institutions in the Eastern Regional Health Authority (ERHA).

This, the first ever study of Travellers and palliative care, confirms that Travellers in Ireland seldom use the palliative care services, and that this is partly because of cultural differences and partly because of institutional barriers.

Traveller culture today incorporates much of what would traditionally be accepted as settled culture - not surprisingly, after centuries of close contact - but some differences remain. For instance, in the context of burial and bereavement, most Travellers reject cremation as a 'settled practice' and consider the maintenance of graves very important. The importance of the extended family means Travellers mostly rely for support on family members, rather than on professionals, and they have a strong preference to die at home, rather than in institutions such as a hospice or hospital.

Institutional barriers include a lack of facilities to accommodate large, extended Traveller families when they come to visit a relative in a hospice or hospital, and the staff's lack of awareness of Traveller culture.

These problems call for imaginative and innovative approaches to service organisation, content and delivery. We need to change our attitudes, approaches and actions. With that in mind, we have recommended several practical initiatives which should help to address biases that might exist in the system.

Recommendations:

1. Data collection:

- The National Cancer Register and the health services should record ethnicity. This simple measure would greatly add to the information available on the health status of Travellers and other ethnic minorities in Ireland.

2. Education and training:

- Palliative care staff should be educated about possible grief reactions, and different rituals and cultural attitudes to dying, death and bereavement. In particular, training and courses on Traveller culture should be provided for health and palliative care professionals.

3. Communication and liaison:

- The health services should devise culturally-appropriate information campaigns to inform the Travelling community about the range of palliative care services available, and about their entitlements to the services.
- Service providers and the Travelling community must work together to identify

issues and to eliminate the barriers that prevent Travellers accessing palliative care services. Communication should be fostered between the palliative care services and the Travelling community, to help develop patient-centred and culturally-sensitive care.

- There may be a role for a Traveller to act as liaison officer between palliative care staff and the Travelling community.

4. Access to services:

- The health services could explore more acceptable ways of providing care and support to Travellers, such as palliative care in a general hospital setting, rather than a hospice, and hospice homecare to families caring for a relative at home.

- Palliative care services need to find ways to accommodate different rituals and cultures as much as possible.

- Institutions and staff need to find ways to accommodate and deal sensitively with the large extended Traveller families wanting to visit the sick and dying, and the overcrowding that can sometimes result.

- Medical and professional staff may need to take extra time, or find other means to explain medical and technical matters to people with limited access to written information. Good communication is essential.

If these recommendations are implemented, the result should be a better palliative care service that benefits not just Travellers, but the many other ethnic minorities now settling in Ireland, and indeed, the whole of our society.

Our society is increasingly diverse, both culturally and ethnically. But ethnic diversity is not new to Ireland, and we have long had our own indigenous ethnic minority, the Travelling community. Travellers are however, often overlooked and forgotten, not least when it comes to the health services. Diversity brings blessings and challenges, and challenges especially for the health services. Palliative care is no exception: the 2001 report of the National Advisory Council on Palliative Care (NACPC) plans the way forward for this specialist area, and recognizes that the needs of ethnic minorities, and specifically Travellers, must be addressed. ‘Traveller Health: a National Strategy 2002 – 2005’ published by the Department of Health and Children in 2002, (hereafter called the Traveller Health Strategy) highlights many of the problems facing Travellers with regard to their health and use of health services. Pavee Point¹ notes that: ‘Travellers inhabit two worlds - the settled world and the Traveller world’ (Pavee Point 2001). Irish health services, from primary through to hospital and tertiary care are modeled on the settled community’s world. The Traveller population in Ireland has a poorer health status and a lower life expectancy than the rest of the Irish population (Barry *et al* 1987). There is a lack of current information on Travellers’ use of health services (Van Doorslaer *et al* 2001) although the recent Traveller Health Strategy goes some way towards identifying areas for action. Anecdotal evidence suggests that Travellers have little interaction with hospice services.

The World Health Organization defines palliative care as ‘the active, total care of patients whose disease is no longer responsive to curative treatment’ (WHO 1990). The principles or values underpinning palliative care include open communication, symptom management, patient autonomy and recognition of the importance of the family. Specialist palliative care is provided by a variety of health care workers with a strong emphasis on multidisciplinary team working.

There is no Irish or international literature specific to Irish Travellers’ use of specialist palliative care services. The Traveller Health Strategy noted that there was no specific identifier of travellers within the existing health data systems in use in hospitals or the community. Research in Britain and Australia shows that ethnic minorities under-use palliative care services (Smaje and Field 1997). Reasons for under-use may be varied; there may be clinical (e.g. lower incidence of cancer), cultural or organisational /access reasons (Karim *et al* 2000). There is some evidence of passive prejudice whereby minorities are under-referred (Karim *et al* 2000, McNamara *et al* 2001).

This study

The aim of this study is to gather evidence to inform an understanding of the context within which Travellers in the Eastern Regional Health Authority (ERHA)¹ above may use palliative care services, and their views and experiences of service provision. The objectives of this study are to describe:

- Travellers’ knowledge about hospice and palliative care in the ERHA
- Travellers’ attitudes to cancer, serious illness, death and dying and hospice and/or

¹ Pavee Point is a partnership of Irish Travellers and settled people working to improve the lives of Irish Travellers through social justice, solidarity, socio-economic development and human rights. www.paveepoint.ie

- palliative care services
- Specialist palliative care staff's experience of caring for travellers in the Eastern Regional Health Authority

Methodology

In 1998 there were approximately 1,300 Traveller families in the then Eastern Health Board (Pavee Point 2001). There are a number of active Traveller organisations in this region (e.g. Pavee Point, The Irish Travellers Movement, and The Parish of the Travelling People) as well as a Traveller Health Unit funded by the government. The Working Group on Traveller Ethics and Research proposed in The Traveller Health Strategy had not been established when this research project was planned. Ethical approval for the study was obtained from St Francis Hospice Research Ethics Committee. As little is currently known about Travellers' knowledge about and attitudes towards palliative and bereavement care we employed a qualitative approach. Qualitative methods such as focus group discussions are widely accepted (Van Doorslaer *et al* 2001, Silverman 1999, Morgan 1988, Kreuger 1994, Kane and O'Reilly-De Brun 2001). Madriz (2000) notes that focus group discussions enable the generation of material such as 'collective testimonies and group narratives'. She also notes that they can play an important part in providing participants, particularly from minority groups with a safe environment to discuss issues. For this study the qualitative methods we chose were focus group discussions and interviews, in order to gain an in-depth understanding of the issues and to 'reach parts other methods cannot reach' (Pope and Mays 1995). This approach provides a context in which participants respect each other as colleagues with valid knowledge and skills and all participants can make valued contributions. Often the very process of participatory research can have an inbuilt dynamic by which those whose health and whose practices are being studied can be empowered; they may gain a deeper understanding of the issues and, consequently, learn something through the process.

A quantitative survey questionnaire survey was conducted with palliative care staff.

Focus Group Discussions

The following table lists the location of the groups and the numbers of participants.

Table 1: Focus Groups with Travellers

Location of group	No. of participants
Dublin city	6
Bray, Co Wicklow	8
Wicklow town	9
Balbriggan, North Co. Dublin	6
Coolock, North Dublin	3
Total	32

Initially we had hoped to reach 'ordinary' Travellers not previously involved in health services education or research. However, experienced researchers, Traveller training course co-ordinators and Travellers themselves advised us to use existing structures such as training courses and primary health care courses, as an appropriate way to approach groups of Travellers. Many course co-ordinators welcomed the opportunity

to raise palliative care with their groups as they had yet to discuss death, dying and bereavement as part of the standard course.

Information on existing Traveller groups was gathered from a variety of sources. Pavee Point provided information on primary health care courses running in the region; also the Irish Traveller Movement has a list of member groups throughout the country². Potential groups were selected on the basis of obtaining a geographical spread across the ERHA region. Groups were contacted by telephone and post, and five groups agreed to take part in the research.

Using pre-existing groups meant that participants in the focus group discussions would know each other and existing group dynamics might affect the extent to which people felt comfortable discussing the issues and offering their opinions. Given the nature of the Traveller community, however most Travellers, even if not part of an established group, would know each other, or know of each other. In this case it was noted that many members felt comfortable contradicting each other and dominance of the conversation by any one person was avoided, through careful facilitation, as much as possible. The focus group topic guideline is presented in Appendix 1. Five focus group discussions were conducted with women Travellers. Unfortunately, the recruitment of male participants proved unsuccessful, and this has been a common problem in other research projects involving Travellers (Van Doorslaer *et al* 2001). Therefore the information presented in this report as representing the opinions of Travellers, actually represents the opinions of Traveller women. The age group was mixed and ranged from late teens to late 60s.

The groups were organised by the group co-ordinators or trainers, and verbal consent to the discussion was sought at the start of each group. It was stressed that participation was voluntary and participants had full permission to withdraw at any point. Only one person chose to leave a discussion. At the end of each discussion, participants were thanked for their contributions by the researcher who also ensured that no one was too upset by memories evoked by discussions. In some cases course co-ordinators or trainers were asked to follow up on a number of participants who had talked about their own recent bereavements.

Interviews with palliative care staff

One to one interviews were conducted with specialist palliative care professionals from a number of disciplines including palliative care consultants, home care nurses, acute hospital palliative care nurses and social workers in the ERHA. Using the Irish Association for Palliative Care directory of services in Ireland (2002), staff participants were selected on the basis of profession and work location in order to obtain a range of opinions and experiences. It was considered important to talk to all the palliative medicine consultants working in the region. Purposeful sampling (Patton 1990) was used to obtain the specific information required for this study.

The unstructured interviews explored staff experiences and views of caring for members of the Travelling community. On three occasions, service providers themselves suggested that staff take part together in group discussions as opposed to individual interviews. The groups varied in number of participants from two to five.

² www.itmtrav.com

Table 2: Specialist palliative care staff

Speciality	Method	Number of participants
Medical directors/consultants	Interview / focus group	4
Social workers	Interview	2
Specialist palliative care nurses	Interview	3
Home care nurses	Interview / focus group	7
Total		16

The survey

A questionnaire based on these interviews and on pre-existing questionnaires (O'Donovan *et al* 1995), was then designed (see Appendix 2). The aim was to survey all ERHA palliative care staff (approximately 230). The questionnaire enquired about the number of Travellers referred; recording of ethnic group and whether 'Traveller' is recorded as a separate group; specific provision for Travellers including staff training; personal experiences with caring for Travellers and their identified needs. A total of 215 questionnaires were distributed to eight organisations that provide specialist palliative care services; 81 completed questionnaires were returned, a response-rate of 38%.

Analysis

All the focus group discussions were audio recorded and transcribed. Qualitative analysis using a phenomenological approach was used. In-depth analysis was facilitated through use of QSR Nudist software. The survey data was analysed using the Datadesk software package.

The impact of this research on the Traveller participants

Although the aim of this research was not to measure in any definite way what impact it might have on the participants, certain reactions to the research were obvious and worth noting. All of the Traveller groups had been contacted prior to being visited and information regarding the nature of the study and their involvement was provided. In most cases group leaders or course co-ordinators prepared the groups for the discussion by introducing the concepts of end of life care, cancer and hospice care. However many participants were still unclear about what was to be discussed and asked many questions about the meaning of the terms hospice and palliative care. On some occasions this made it difficult to measure the extent of their knowledge without making them feel embarrassed about their lack of knowledge. It also placed an onus on the researcher to clarify the concepts for them in order to proceed with the discussion. Therefore in most cases the transfer of information was a two-way process.

In every group there were participants who were uncomfortable with the discussion. Although every group was made aware that they could leave at any stage if they felt too uncomfortable, only one participant left. In many other cases, frequent self blessing and touching of the wooden tables occurred, as well as including expressions such as *'may God preserve us'* or *'Lord have mercy on her'* as they spoke. Many of the Traveller participants were talking about issues that are almost seen as taboo and for many there still exists a strong superstition about talking about death, dying and cancer.

The taboo was confirmed when we tried to organise a visit by a group to St Francis Hospice. It was thought that a visit followed by a discussion might provide some interesting information about perceptions of palliative care. It was also thought that a successful visit may be a way of informing Travellers in general of palliative care and other visits could be arranged. However, the group decided that they would not feel comfortable going to the hospice. This group also declined to take part in the research. The group leader, a Traveller primary health care course co-ordinator gave her impression of this situation:

When the group found out that it was a hospital for terminal illnesses their answer was quick and unanimous: we would not like to visit such a place. They all said because afterwards they would be thinking about it all the time, they would carry back with them all the thoughts about death. My impression was that there is a general fear around death and a sense that it is an area you don't go close to unless you have to. I got the impression they thought that being close to death when they were not meant to would have negative consequences for them. Normally when any negative thing is mentioned women would touch wood or cross themselves, as if by the simple fact of mentioning that negative could be attracted to them. With death I suppose this fear is even bigger. (Personal correspondence)

This study will identify some of the difficulties, real or perceived, that impact on contacts between the Travelling community and specialist palliative care services. Palliative care has the potential to improve the care and quality of life of people who have progressive fatal illness. If there are cultural or institutional barriers, which prevent Travellers accessing palliative care, identifying these barriers is the first step to addressing them.

Traveller Health in Ireland

Travellers are an indigenous minority group who have been part of Irish society for centuries. They have a shared history, value system, language, traditions and customs. As a nomadic ethnic group, there is some dispute as to whether Irish Travellers are a distinct group or whether they are related to European Gypsies and Roma arriving from India in the 16th Century (Oakley 1993). Whatever the origin of Irish Travellers they share a nomadic tradition with other gypsy groups and unfortunately they also share a long history of persecution, rejection and social exclusion with their European counterparts. Their distinctive culture, based on nomadic traditions, sets them apart from the 'settled' community. As highlighted by Pavee Point:

Moving from one place to another has given rise to a distinct Traveller way of looking at the world. Nomadism is often described as a state of mind. Even where Travellers occupy houses they regard accommodation as essentially temporary in nature – as do other nomadic peoples around the world. A Traveller living in a house is still a Traveller – just as an Irish person living in Britain is still Irish. (Pavee Point 2001)

The report of the Task Force on the Travelling Community (1995) notes that nomadism can take a range of forms:

Travellers' nomadism includes those who are constantly on the move, those who move out from a fixed base for a part of any year, and those who are sedentary for many years and then move on.

Fay and Crowley (2001) highlight the implications that nomadism can have on the provision of health services. This particularly relates to:

- Medical records, e.g. the need for patient held records and improved systems for transferring records.
- Postal correspondence with patients and the need for agreed channels of communication.
- Medical cards and the need for extended validity and simplified procedures to enable access to general practitioners (GPs) for Travellers moving into or through an area.
- Traveller-specific outreach services to complement and improve access to mainstream services.

Traveller demographics

Travellers have a very distinctive population profile. They comprise approximately 1% of the population of Ireland, with 23,000 Travellers living in the Republic of Ireland and 1,500 in Northern Ireland. A further 15,000 Irish Travellers are reported to live in Great Britain and 7,000 in the USA.

Age structure

The Traveller community identified during the course of the 2002 census had a markedly different age structure from that of the population in general. Of the Travellers distinguished by enumerators, 43% were aged less than 15 years compared with slightly less than 25% for the population in general. Older Travellers (i.e. those aged 65 years and over) accounted for just 3% of the total Traveller population while

the corresponding proportion for the settled population was approximately 14%. The high birth rate in the Traveller Community is reflected in the high proportion in the younger age groups. According to the 2002 census the number of Travellers counted in temporary private households, halting sites, encampments, caravans and mobile homes was 7,365 where as the number in permanent households was 11,098.

There is tremendous disparity in health status between the Travelling community and the settled population in Ireland. To date, there has been only one baseline Traveller health status survey on a national level, conducted by the Health Research Board in 1987. The main findings included:

- Traveller infant mortality is three times greater than the national average.
- Settled men have a life expectancy of 75 years where that of Traveller men is 65 years.
- Settled women have a life expectancy of 78 in comparison to a life expectancy of 65 years for Traveller women.
- Travellers have higher death rates for all causes of death compared with the settled community (Barry *et al* 1987).

Another study notes that:

- Travellers have more than double the national rate of still births.
- Only 1 in 20 live over the age of 50 (O'Brien 2000).

Travellers today are only now achieving a life expectancy achieved by the settled community in the 1940s (Barry *et al* 1987).

The death rate from accidents, metabolic disorders, respiratory ailments and congenital problems is significantly higher among Travellers compared to the national rates (O'Brien 2000). Murphy (2000) proposes that many of the deaths in the Traveller community arise out of the living conditions and the social exclusion, which most Travellers live with on a daily basis.

UK studies support the Irish findings regarding health and have also shown high perinatal and infant mortality among Travellers, poor health (such as a high rate of childhood accidents), higher death rates from cardiovascular disease and a higher incidence of asthma (Van Cleemput 2000). The Irish Sudden Infant Death Association reports show a higher incidence of cot deaths among travellers (typically **0.7 per 1000** live birth nationally, **2.2 per 1000** live births among travellers).

The high levels of **childhood mortality** naturally impacts on the Traveller community in many ways. With so many children dying, the loss of a child becomes a common experience to all. Helleiner (2000) notes that despite improved child survival rates, the still common experience of infant and child mortality ensures a pervasive sense of the precariousness of children's lives that is expressed in intense concern over their illnesses and potential for accidents. Should a medical crisis arise, families experiencing the situation are surrounded by a wide group of relatives who remain closely involved on a daily basis until the situation eases. Once again the widely shared experience of child mortality ensures that the illness of a child is intensely experienced by many beyond the immediate family. Lower life expectancy among Travellers ensures that experience of death and dying is widespread and frequent.

Accommodation and Traveller health

Although many Travellers have difficulty obtaining adequate health care, there is a division between those settled in permanent sites and those constantly on the move. The Clondalkin Travellers Development Group (CTDG) studied Traveller accommodation status in the Clondalkin (west Dublin) area in 1999. The study highlights many of the issues for Travellers in relation to accommodation on a national level. The lack of a clean water supply, good sanitation facilities or regular refuse collection (leading to rat infestation) may have a direct influence on Traveller health. The CTDG also conducted a survey with a number of GPs and public health nurses in the area. Those interviewed felt that many of the illnesses that Travellers present with could be linked with poor living conditions (Howley 2001). The location of many of these sites and camps also presented problems, often located on wasteland near dumps, canals or electricity pylons. In many cases they are also far removed from public transport routes, which further reduces access to local health services. Children also fare badly as a result of the living conditions: as well as being distanced from many play and sports amenities, they usually lack any play facilities on site.

Another factor that affects the health status of Travellers is their cultural practice of maintaining and encouraging consanguineous unions. It is common for first cousins to marry. The incidence of first cousin marriage in the Traveller population has been recorded as 19% compared with 0.16% in the settled population (Barry *et al* 1997). Marrying within the family may have serious health implications. A national population survey on the health of Travellers found that Irish Travellers had a greater prevalence of congenital abnormalities at birth in comparison to the settled community in the Eastern Health Board (5.5% v 2.9%) and a significant difference in the prevalence of recessive metabolic conditions (12.4/1000 v 1.3/1000) (Barry *et al* 1997).

Anecdotal evidence among those who work with Travellers and those that work in the health services points towards only 3% of Travellers dying of cancer per year (Monaghan, 2002). Travellers may not live long enough to die from cancer, a disease commoner in older people; Travellers may die from other diseases and disorders. Hill and Penso (1995) note how in England very little information on the incidence of cancer in the ethnic population is available because ethnic origin has not been recorded in cancer registration data. In Ireland, the National Cancer Register does not record ethnic identity. Most hospitals do not record ethnic identity. The incidence of cancer among Travellers, or of other progressive fatal illnesses where palliative care services are traditionally involved (motor neurone disease or AIDS) is not known. The Irish Motor Neurone Disease Association is not aware of a traveller developing motor neurone disease in the ERHA / EHB in the last ten years.

Strategies to improve Traveller health

Since 1992, Pavee Point has been involved in targeting the many health issues that Travellers face. In 1994, Pavee Point in partnership with the Eastern Health Board (EHB) established the **Primary Health Care for Travellers** project. This project aimed to improve the health status and quality of life of the Traveller community in Community Care Area 6 of the EHB. The project involved establishing a model of Traveller participation in the promotion of health. This in turn involved developing the skills of Traveller women in providing community-based health services, assisting in creating a dialogue between Travellers and health service providers, and

highlighting the perceived gaps and inequalities in health care service provision to Travellers. The project has been successful in exploring the existing health care system from the perspective of its consumers, in this case the Travelling community.

The Department of Health and Children launched its report *Traveller Health: a National Strategy 2002 - 2005*, in February 2002. This document is a blue-print containing 122 separate actions to improve health standards among the country's Travelling population. The Minister for Health and Children, launching the strategy, claimed the strategy's effectiveness would be determined by the willingness of health service staff, administrators and Travellers themselves, to work towards changing the knowledge and attitudes of the settled community and among the Traveller community itself in relation to health issues.

In every culture, major life experiences of health and illness are interpreted through a substantial and integral body of beliefs, knowledge and practices (Scotch 1963). Any attempt to impact on the health practices of individuals must refer to the broad cultural basis for behaviour. Medicine is part of culture: once a diagnosis or treatment is taken out of its cultural context, its cultural significance and the ability to predict compliance, outcomes and health promotion is lost. Information on specific cultural beliefs can act as a framework to understanding the health needs and required treatments and anticipating the cultural factors that may act as barriers to accessing health services. Travellers are not however the only stakeholders in this issue. The providers of health care services must also assume responsibility for the issue of Traveller health. The recognition of Traveller gypsies as a distinct ethnic group may lead to better understanding of their perception of health, illness, prevention, and the role of health services (Feder 1989).

In Summary

There are an estimated 23,000 Travellers in the Republic of Ireland, with a further 1,500 in Northern Ireland, and some 15,000 Irish Travellers in Britain and 7,000 in the USA. The age structure of the Traveller community in the Republic of Ireland is markedly different from that of the settled population: 43% of Travellers are under 15, compared with 25% for the population in general; and only 3% of Travellers are over 65 (compared with 14% nationally). This reflects Travellers' higher fertility and birth rate, and their higher infant mortality, difficult living conditions, poorer health and lower life expectancy.

The National Cancer Registry does not record ethnicity, so the numbers of Travellers contracting and dying from cancer are not known. However, anecdotal evidence suggests that only 3% of Travellers deaths are from cancer every year, compared with 25% of deaths in settled people. More research is needed before we can say if this is because Travellers generally die younger, and so seldom live long enough to contract cancer.

New initiatives aimed at improving Travellers' health status are now being established, following publication of the Department of Health and Children's report, Traveller Health: a National Strategy 2002-2005. Many of these initiatives are aimed at involving the Traveller community more in shaping and participating in health measures.

Palliative care is concerned with the physical, psychosocial and spiritual care of patients with life-threatening disease and of their families (Saunders 1996). Palliative medicine or palliative care are the labels given to the modern package of skills, procedures and practices that have been sponsored and refined mainly within the hospice movement (Dickenson *et al* 2000). According to Field, the ideology of the hospice movement centres around three core ideas: holistic care; multidisciplinary teams that work in a non-hierarchical fashion; and the incorporation of the patient's family as part of the unit to receive care (Field *et al* 1993 cited by Bradbury 1999). Efforts are made to address the fears and anxieties of the dying person and to care for them in a caring and affectionate environment (Lattanzi *et al* 1995 cited by Bradbury 1999).

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

In this way palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

For those working in palliative care and in hospice care, death is accepted as a natural occurrence and the fulfilment of human life on earth. It is an event that occurs only once for each person and its uniqueness means that great consideration should be given to the circumstances surrounding it (Rees 2000). In the course of gathering the data for this study, palliative care service providers talked about the philosophy of palliative care, the palliative care approach:

I think that palliative care is flexible. Not for them [patients] to fit into what our model is, but for us to be flexible around what's comfortable for them, particularly in their perceptions of how they want to die. If they have particular religious or spiritual aspects or ways of thinking about their own death and dying, that we would try to accommodate them. (Specialist palliative care nurse)

Irish hospice and palliative care services

Hospice care in Ireland began in the late nineteenth century with the founding of Our Lady's Hospice in Harold's Cross, Dublin and St Patrick's Hospital in Cork. In the 1970s and 1980s specialist palliative care services were developed by voluntary and charitable agencies with varying degrees of support from statutory services. The need for a national approach to palliative care services was recognised in the first health strategy, 'Shaping a Healthier Future' (Department of Health 1994) and first Cancer Strategy (Department of Health 1996) although it was not until the 2001 report of the National Advisory Committee for Palliative Care was published that a national strategy was outlined. Palliative care services traditionally care for patients with cancer and motor neurone disease. The role of specialist palliative care services in the care of patients with illnesses other than cancer is a challenge which is being faced by services, but as yet it is not clear what their role is.

This NACPC report recommended regional structures (the Regional Palliative Care Consultative Committee and the Regional Palliative Care Development Committee) to support equitable development and to include the voluntary sector and consumer perspectives. Given that our research was carried out during these developments it should be noted that the following description of services will be changing.

In Ireland, palliative care is provided in a number of hospices and by palliative care teams in hospitals and in the home. The Health Strategy, "Quality and Fairness a Health System for you" (Department of Health and Children 2001) recommends that a national palliative care service be developed, in accordance with the NACPC recommendations. There are currently five specialist palliative care in-patient units (hospices) in Ireland:

- Marymount Hospice, Cork
- Milford Care Centre, Limerick
- Our Lady's Hospice, Harold's Cross, Dublin
- St Francis Hospice, Raheny, Dublin
- Galway Hospice Foundation

Palliative care in-patient units in Sligo (the North West Hospice) and in Donegal, are also developing. In all areas, there are hospice home-care teams. At the time of this research there were 10 consultant physicians in palliative medicine in Ireland: four in the ERHA area and two in the Southern Health Board, one in each of the Mid-Western Health Board, the South-Eastern Health Board, the Western Health Board, the North-Western Health Board and North-Eastern Health Board areas.

Each specialist palliative care in-patient unit has specialist palliative care teams working in the community. The specialist units also provide a hospice day care service for patients. Some acute hospitals also provide a specialist palliative care service. Patients are referred to palliative or hospice services by their family doctor (GP) or by their hospital consultant.

EHRA Services

The ERHA comprised of three area health boards: the Northern, East Coast and South Western Area Health Boards which are responsible for the provision of health and personal social services to the 1.5 million people living in Counties Dublin, Kildare and Wicklow. The boards were established in March 2000, when the Eastern Health

Board was dissolved. Palliative care services in the ERHA, as in the rest of the country, have developed *ad hoc* rather than as part of an overall comprehensive plan.



Figure 1: The geographical area serviced by the Eastern Regional Health Authority.
Source: (www.erha.ie)

There are two comprehensive specialist palliative care services with in-patient, hospice home care and hospice day care services (St Francis Hospice and Our Lady's Hospice). Beaumont, Our Lady's Hospital for Sick Children, St James', St Luke's and St Vincent's Hospitals have consultant-led specialist palliative care teams providing consultative advisory services. James Connolly Memorial Hospital has a nurse-led specialist palliative care service (the consultant post is vacant). There are nurse only hospice home care services in Wicklow, and a medical director-led hospice in-patient service at St Brigid's Hospice in Kildare.

Data from our interviews and focus group discussions with palliative care service providers from the ERHA provide a first hand insight into and description of the services currently available. Palliative medicine doctors, home-care nurses, social workers and clinical nurse specialists in palliative care gave their own impressions of the services. Palliative care services in the ERHA are delivered by multidisciplinary teams that work closely together to address the needs of the patients and their families.

In-patient hospice care: Patients may be admitted for the management of complex symptoms, complex psychosocial care, respite where families or patients may need a break from care in the home, or for rehabilitation, and discharged home. Patients are also admitted for specialist palliative care until death.

Hospice Day Care: This service provides specialist palliative care and social support for patients. People who are well enough to travel into the hospice for the day, use this service. Nursing, medical, social work, pastoral and rehabilitation staff provide care.

Hospice Homecare: Hospice homecare teams provide an advisory specialist palliative care service, arranged by the patient's GP or by the discharging doctor in hospital. Homecare services are provided by palliative care doctors, who usually do first visits and medical reviews when needed, and homecare nurses, social workers and other paramedical staff. Homecare nurses work as part of teams either based in the community, working from a hospice, hospital or community base. Homecare nurses in this study felt that they '*enable and empower families to nurse their loved ones at home*' and can offer spiritual and emotional support for both the patient and the family. The homecare nurses have a specific remit in terms of caring for patients, assessing symptoms, advising about treatment and administering medication. The frequency of a nurse's visits will depend on the assessment made by the nurse, the local GP or the hospice doctor. Their role is to enhance the level of care by supplementing existing services provided by GPs and public health nurses rather than replacing them.

Acute hospital services: Hospital palliative care services are usually consultant-led with specialist nurses, social workers, occasionally non-consultant hospital doctors and administrative support providing the service. Teams receive referrals from the patient's consultant and provide advice, support and education. There are teams in six ERHA hospitals including Our Lady's Hospital for Sick Children, with plans to develop services in other ERHA hospitals in the next one to two years.

Psychosocial and bereavement support: Social work is another service provided under the palliative care umbrella. In a hospice setting, social workers will often provide support for the homecare and the hospice daycare service as well as the in-patient unit. The work involved can range from direct counselling of the patient to helping the family communicate with each other and support everyone involved. Social workers help patients and families find practical solutions to problems, and will often support and promote the psychosocial care given by nurses and doctors. Social workers are also involved in bereavement services which are offered to the families and friends of patients who have used the palliative care services.

Palliative care and children: Palliative care for children is delivered differently from services for adults. Many children requiring palliative care have life-limiting conditions, as opposed to advanced terminal conditions, and may survive for many years with these life-limiting conditions. Where required, palliative care for children is usually provided at home, where the family is closely supported by their GP, public health nurse and the specialist palliative care team (where available). A needs assessment of paediatric palliative care is currently being undertaken. Our Lady's Hospital for Sick Children at Crumlin has specialist palliative medicine consultant sessions. Children in need of specialist palliative care in other settings, including the home are supported by adult Palliative Care Services.

In Summary

Hospice care began in Ireland in the late nineteenth century, with the founding of Our Lady's Hospice for the Dying in Harold's Cross, Dublin and St Patrick's Hospital, Cork. However, a century was to elapse before the service was expanded to any extent. Then, in the 1970s and 1980s, several specialist palliative care services were established, mostly by voluntary and charitable agencies. In 2001, the National Advisory Committee on Palliative Care published a report which was adopted by the Government as policy.

Traditionally, palliative care is provided for people with certain terminal illnesses (notably cancer and motor neurone disease). The services include hospice (both in-patient and daycare), hospital in-patient and hospice homecare. Palliative care is characterised by multi-disciplinary teamwork, involving a wide range of expertise, such as palliative medicine specialists, specialist nurses, social workers, occupational therapists and chaplains.

Culture and customs of Travellers

This chapter explores the behaviour, customs and traditions of the Travelling community in relation to illness, dying, death and bereavement. By locating the information and available literature within the cultural framework of Traveller culture, people from outside this framework, non-Travellers, may reach a greater understanding of how Travellers may react in terms of behaviours, customs and traditions. First, we explore how culture dictates ritual, custom, tradition and behaviour. Then some Traveller customs, traditions and practices around illness, dying, death and bereavement, are outlined. The overall objective is to provide real examples, which may inform those working with Travellers about the many varied responses to this major life event.

Culture and ethnicity

Culture has been defined as a finite and self-sufficient body of beliefs, customs and traditions (Keesing 1981) and as a way of life of a people (Barley 1986). Every culture has its own particular practices, rituals and customs that provide its members with patterns of appropriate behaviour through the major events of life. **Ethnicity** is a concept that embraces more than a set of customs and traditions and is argued to confer the basic identity of an individual, a sense of belonging and a sense of self. The term 'ethnicity' then, describes a group of people who share characteristics that give them distinctiveness and a difference from others (Price and Cortis 2000 cited in Jack *et al* 2001).

Death, an inevitable human universal, requires specific rituals and traditions to guide people through difficult, confusing and deeply distressing transitions. Death is not simply a clinical fact; it has a social and cultural impact on society and its members. What death means to different people across different times and cultures varies significantly (Van Doorslaer and Keegan 2001). Ritual practices are used by groups to define the meaning of death, the cause of death, the bereaved, the relationship between the bereaved and one another, the meaning of life and major societal values (Rosenblatt 1997). To gain a greater understanding of how people conceptualise death, dying and bereavement it is necessary to gain an insight into cultural traditions that govern group behaviour and to a certain extent influence the individual response to these situations. Culture is an important lens through which to explore the health services. It provides an insight into what influences behaviour and experience, and it is the foundation by which people live their lives. Culture is particularly relevant to this study as it provides the explanatory framework through which to consider:

- Sensitivity to cultural diversity and responses to that diversity
- Illness perception
- Care patterns and the cultural appropriateness of the care
- Issues around dying
- Issues around death and after death

A meeting of cultures is really a meeting of understandings. Cultural beliefs may be invisible to those who hold them because they are essentially unquestioned assumptions about the world. When two sets of beliefs and practices encounter each other issues can arise. In the case of delivering palliative care to Travellers, a group holding one set of beliefs is in the position of delivering health care to a group holding a different set of beliefs.

Different cultural perceptions of illness influence the way patients seek treatment, their compliance with medication regimens, perceived control and responsibility and ownership of their problem (Nyatanga 1997). For example, a patient may perceive her/his illness as punishment for sinful behaviour. Another perception may be to view death as fatalistic, as meant to be, and therefore accept it graciously (Nyatanga 2002). Seale (1998) draws on a comprehensive review of sociological, anthropological and historical studies as well as his own research to demonstrate the great variability that exists in human social constructions for managing death.

In some cultures such as India, Nepal, China, Pakistan, Greece and many other small group societies around the world, death affects not only the immediate family but also the community. The disposal of the dead and the accompanying mourning then becomes a social affair. Crying, weeping, sobbing, and wailing in public, expressing all emotions and not making any attempt to hide emotions is an accepted part of the social ritual in such cultures (Laungani and Young 1997). Funerals in these societies are public events and anyone who is in any way related to the deceased or to the bereaved family attends and participates in most of the ensuing rituals and ceremonies. The family members of the deceased accept and welcome such visitations and look upon them as part of the acceptable cultural norms. However, in many north European societies such as Britain, the Scandinavian countries and the USA the aftermath of death, to a large extent, is viewed as a private event affecting the immediate family members. Free expression of emotion may not be expressly discouraged but is certainly not encouraged. Often the social expectation is that those who were not invited to the funeral ceremony, such as social acquaintances, work associates and distant relatives of the deceased, would write to the family members to offer their condolences (Laungani and Young 1997). In some societies, the rituals for dealing with death are spread out in a series of ceremonies that span months or even years (Rosenblatt 1997). Often those outside the mourner's culture may not know what to say or do. There may be attempts to mute or entirely stop practices that seem alien. In society at large there may be no tolerance for certain rituals. For example, community authorities and neighbours may not tolerate the destroying of property of the deceased or loud continual wailing (Rosenblatt 1997).

Rituals and customs practised around death vary from group to group and among individuals depending on the circumstance of the death and the preferences of the bereaved. It is important to note that Travellers, just like every other ethnic group, select from a range of rituals and customs prescribed by their cultural backgrounds, which change over time. There is no one certain way that Travellers behave around death, dying and bereavement, but there are guidelines dictated by deeply held common beliefs. Ultimately, 'at the centre of all the ritual and expression is a human response to a loved one who has died' (McDonagh and McCormack 2002).

Traveller Traditions

The ways in which one understands the 'workings of the world' come from deep inside one's own individual enculturation and socialisation. In most cases the system or structure which the individual knows is seen as the best, and any unfamiliar system is seen as conflicting, unknown and confusing (Van Doorslaer *et al*, 2002). The Traveller community has a rich body of ritual and customs, which help to ritualise the grieving process (O'Brien 2000). O'Brien also suggests that Travellers have held onto a core body of ritual which resembles that both of Ireland years ago and of Ireland

today. Travellers' beliefs about causes and cures of ill health are based in a different cultural understanding of health than those of the settled community. Traveller culture and identity has a relevance to health policy and provision because it:

- shapes Travellers' definition of health, perceptions of illness and responses to illness
- influences the manner in which Travellers take up health services
- challenges health policy and provision to be accessible and culturally appropriate to Travellers if equitable health status outcomes are to be achieved (Fay and Crowley 2001).

Nomadism

Nomadism is central to the Traveller community's way of life and is key to the worldview of being a Traveller. Nomadism is a mindset reflected in the bonds of kinship, which are at the heart of how this community experiences its identity and organises and structures itself (O'Brien 2000). Travellers' experience of bereavement and the customs associated with it express the close family ties, extended family bonds and religious and folk beliefs of this distinct culture. Death threatens the survival of this community. It breaks up the close-knit ties, so all from far and near gather in solidarity around the dead person, to make sure that those ties are not completely broken. Travelling is only part of what it means to be nomadic. Yet travelling enables some Travellers to come to terms with death. Moving away from the location of death is often a way of coping as is the seasonal revisiting of sites in which bereavements have occurred. As the Traveller community has become more restricted in their mobility due to laws and social attitudes, traditional coping and support systems, which are essential to grieving for the Traveller community, could also be threatened (O'Brien 2000).

The Travelling community has always lived in large family groups. Each immediate family would traditionally be large, with up to 10-15 children per family being common. In recent years family size has reduced but families of 5-7 children are still common. Relations are considered as part of the close family unit, with aunts, uncles, grandparents and in-laws living close together on the same site or area. Due to the cultural practice of maintaining and encouraging marriage within families, it is common practice for first cousins to marry.

Traveller people have been brought up to be very close to each other and no body has ever tried to change it and I don't think anyone wants to change it, you know we are happy enough the way we are. (Traveller)

At times of illness, the family is the priority; they will put other demands on their time (such as jobs or courses) on hold:

L: There'd be an awful lot of support from the family members to each other, that's very important. It's probably the same in the settled. You have to stick together.

H: Stick together till everything's over.

B: Some people will have very important things to do and they'd drop it no matter what and they stay with the person, console one another.

Facilitator: So you would really put everything on hold for that time?

B: Yeah everything. (Travellers)

Many family members may want to visit Traveller patients in hospital; this can include parents, grandparents, aunts, uncles, cousins etc. This may not fit in with hospital visiting policy and cause friction between staff and other patients and visitors (Van Doorslaer *et al*, 2002). The extended family aspect to Traveller culture can also have implications for patients attending outpatient appointments and when making family appointments (Van Doorslaer *et al*, 2002).

McDonagh and McCormack (2002) stress that the experience of death for Travellers is set within the Christian context and the family network. During the terminal phase of an illness these family relationships become an integral part of the dying process for both patient and family. People seek to spend time with the patient, to see them, to make amends, to disconnect, to remember the past; there is a deep commitment to this duty ingrained within Traveller people. If family is central to the Traveller way of life, then children are central to the family. The nature of the Travelling way of life means children are included in the experiences of dying and death within the family. Children are allowed to see and touch the dead body if they so wish (McDonagh and McCormack 2002). Like adults, children will talk about siblings that have died and on occasions recall the name of the child and the date they died even when this may have happened before they were born (Helleiner 2000).

A specific dimension of the centrality of family is the notion of respect for the elders of the community:

The Travellers respect the elderly to the highest level. The older you are the more respect you get no matter how sick they'd be, that'd be how devoted they'd be, they'd care for them. (Traveller)

Religion and Ritual

Most Travellers are Roman Catholic and believe in the teachings of the Catholic faith, that there is an afterlife and that God and family members who have died before them will be waiting to greet them on their death. For Travellers their faith is central to dying and bereavement; faith is the most important factor for them in making sense of what is happening. Travellers feel that God walks the journey with people in both life and death (McDonagh and McCormack 2002). Faith is expressed largely through prayer. Murphy (2000) notes the key role of prayer in the process of dying and mourning the dead. Traveller prayer is very biblical and in the tradition of lamentation for what could have been and is not. Traditional prayers such as the rosary are said, which encourages participation and involvement of all the family. Religious objects play an important role also:

Usually holy objects and relics, prayer cards and statues, all of which carry the prayers and the hopes of the people who place them there, will surround the person who is dying. If the person is unconscious it's possible that these symbols of faith will be placed around the body, especially around the head. It is important that holy objects don't get put out of sight; they reassure the family and the patient that what ever happens, the person who is dying is protected by the love of God (McDonagh and McCormack 2002).

Most small-scale societies have ritual specialists. The Native American have shamens, for instance. It is important to appreciate the extent to which ritual specialists support those coping with dying and death (Rosenblatt 1997). In Irish society traditionally the priest would have been seen as the spiritual specialist, the doctor as the medical

specialist, the policeman as the representative of the law, etc. In Traveller society the religious, especially the priest, command more respect and authority than any one else.

Well I believe more in the priest than I would in a doctor. But I suppose you'll have to go to a doctor too sometimes. But most Travellers anyhow have more belief in the priest (Connors 1992).

A study carried out with members of the general public and professionals such as priests, social workers and palliative care specialists found that Irish people tend to embrace tradition and ritual around the time of dying and death (Van Doorslaer and Keegan 2001). Travellers practise a range of rituals and customs around illness, dying, death and during bereavement which vary in different regions of Ireland just as they do for those of the settled community. The customs and tradition outlined in this study may not be common to all Traveller family groups; some are particular to individual families. It is also apparent that the settled community practises many of these rituals and customs. As with other populations Travellers have some key aspects to behaviour around dying, death and bereavement, which are common to all, such as the large family gatherings and the deeply held religious beliefs and practices:

Yeah there's a lot that has their own tradition and it depends where you were born and reared up. There's a lot of Travellers that has different culture than we have, probably them all has their own different ways. (Traveller)

Each individual has their own way of coping with bad news and the imminent death of a close one. It is a Traveller tradition to visit the sick and dying in large numbers, for example, and participants in this study noted how large numbers will still visit those sick in hospital. Williams (2003) notes that with Romanies, large groups of people can be expected at the bedside, the tradition being that the dying person should not be left unattended at any time. Everyone who knows the dying person will consider it their right to be present at the bedside, with little regard for visiting hours or rules governing numbers of visitors. Travellers will often seek both conventional medical advice and the help of healers and cures for the same complaint. In Traveller culture it is important for the family to seek blessing for the sick and dying. On occasion 'healers' may visit the dying person. Family members may travel to holy places such as Mount Mellory to pray for the sick person and will visit 'holy people' (priests, nuns, clergy etc.) and 'healers' (McDonagh and McCormack 2002). In this study, using healers was not seen as confined to the older generations. Although insistent that healers are still used, many noted how Travellers did not have as strong a faith in their abilities to heal as they once may have. There is a strong fatalistic belief that if you are meant to die you will. It was also suggested that cancer is not considered an illness that can be cured by healers. The role of religion around the time of dying and immediately after death was frequently mentioned by many of the Travellers and palliative care service providers in this study:

I had a priest in my house praying for three months, mass said inside my house every evening and all me husband's family and all me own family and praying for my daughter. (Traveller)

Bar a few of the younger Traveller participants, most Travellers that participated stressed the overriding importance of the priest at times of illness and imminent death.

The time of death and the time immediately following death is marked by a number of customs and practices. Okely writing about Travellers in Great Britain talks about funerals being the occasion for an unlimited gathering of Travellers, former camp neighbours, associates and indeed any Traveller in the vicinity to pay respects. The composition of the gathering emphasises the unity of all Travellers, transcending political clusters and rivals (Okely 1983). Similar to the gatherings when the person was ill and dying many Travellers gather for the funeral, some may have remained in the area. Participants in this study support the notion of large crowds coming together to bury the deceased.

Religion for Travellers is a central source of comfort and support throughout illness, dying, death and bereavement. Traveller participants in the study stressed this importance of a Catholic burial by describing with horror a non-religious burial ceremony:

He went to a funeral and they didn't even have a mass or nothing...and we would never be able to do that. They just said his whole life he just didn't believe and when he died he just wanted to get buried. We'd never be able to have peace of mind, you'd have to give them the full praise. (Traveller)

Traditionally, there would have been strict eating and cooking practices around the time of death. Chrissie Ward recalls:

You'd never get anybody cookin' or washin' vessels or doin' anything in the home. They wouldn't be interested in that' (Ward 1992).

There is also the possibility of fasting at the time of a funeral (O'Brien 2000). Although none of the women in our focus groups referred to fasting around the time of a death they did refer to a lack of interest in food at this time. Some talked about how at settled people's funerals, food would be provided but that Travellers would not be interested in eating at this time. O'Brien notes how certain keepsakes such as pieces of the dead person's hair are valued by the bereaved. McCann (1992) says photographs are probably the most common keepsakes when all other reminders such as clothes and belongings would routinely be burned. Murphy (2000) talks of his experiences leading Traveller funerals and the manner in which they mourn. He talks of an open, natural grieving process where parents and children, husbands and wives openly cry and talk to their dead relatives in the mortuary, that they 'pour' out their grief.

As with Irish people in general, Travellers would traditionally be waked before their burial. However, as with the settled community, the definition of 'wake' can be vague. It can refer to a session in the pub before the funeral or gathering for drinks afterwards. In its original sense it referred to the ritual of food, drink, storytelling song and games prior to the funeral in the company of the corpse (Van Doorslaer and Keegan 2001). McCann (1992) notes how traditionally the Traveller would be waked with singing, dancing and smoking. One service provider taking part in this study talked of her experience in relation to Travellers waking the deceased noting the similarities to wakes of people from the settled community. One feature more associated with Traveller deaths and wakes is the open-air fire. For those living in houses it is not always feasible to have a large bonfire outside the house, although it does still occur in some areas. In general fires are more common with those living in halting sites. Some participants talked about the lighting of candles by the camp fire

and how some of those in houses travel to the fires to take part in the custom. In other cases they will conduct a wake in the house without a fire:

P: They light a fire and sat around chatting.

K: And get candles.

P: And talk till all hours of the morning.

Facilitator: Was that recently?

M: Four year in May.

Facilitator: Would that be a usual thing to light a fire and sit around?

K: Well that was the old tradition and they still do that, and bring the drink around and every one gathers around the fire and when it hit twelve then they light the candles.

Facilitator: And that would be on sites. Do people in houses do things differently?

K2: They'd come to the camp fire place.

M: Peoples that lives in houses, some of them has a wake in the house.

K: But they don't have no fires. (Travellers)

Funerals and Burials

After death, through the wake, the funeral and the mourning period, alcohol continues to play a large part (Carr 1992). Participants in the focus groups noted that for many Travellers such intensive drinking might be age-related with younger Travellers choosing not to drink. As with many settled Irish funerals, going to the pub for drinks after the funeral is common practice:

A pub would be organised for the funeral, they'd have somewhere hired out for that whole day after the funeral. All the family and relations would go to that pub and have a few drinks. (Traveller)

They go to pubs for the wake and then the day after and the day after that, maybe the week. It's like a meeting place for everyone. (Traveller)

Some women said the drinking lasted beyond the funeral for some grieving Travellers:

A: Some'd be drunk for a week.

K: That's true, they could be drinking up to the first month's mass.

A: Even if the person is dying they cannot handle it and they could be drinking for a month.

Facilitator: And how does that affect things?

K: Sure poor P is still drinking now, he got his wife and daughter killed a few months back. Something like that you cannot recover from it.

L: The drink just numbs the pain, it's not the answer. You are going to have to sober up some day and let reality hit you, they are gone no matter what you do, the drink's not going to take them back. It might end up making you follow them. (Travellers)

Some women felt that drinking would not lessen people's grief and yet it is accepted as a traditional behaviour at the time of dying and death:

N: They try to drink their sorrows away but the sorrow is always there when the drink is gone, init?

M: The next morning it's still the same way.

N: I don't think that helps at all.

B: No it doesn't but that's always been the way, you know. (Travellers)

McDonagh and McCormack (2002) note that large funerals are common among Travellers. Large funerals, a sign of respect to both the family and the person who has died, were also noted by those taking part in the study:

That's one thing about Travellers' funerals as well, even you might not have known that person but you know someone belonging to them, and there'll always be a big funeral. (Traveller)

P: Well Traveller funerals is always big.

L: I've never known a small Traveller funeral.

A: You'd have to have been not liked at all. (Travellers)

Okely (1983) notes that the prestige of the deceased is marked for the last time by the number of vehicles and people who follow the hearse to the graveyard and by the number of wreaths. A man or woman is not only remembered by the number of family assembled, but perhaps more by the number of assembled Travellers without such connections. These demonstrate the extent to which the individual inspired respect and the extent to which she/he is a loss to the community. The burial is the final moment of parting and people can become very emotional at this time:

Everyone would be crying outside going mad. (Traveller)

Contrary to the gradual increase in popularity of cremation among the settled community (Van Doorslaer and Keegan 2001), Travellers reject cremation outright with the simple statement 'we do not believe in it' (Okely 1983). Those that took part in the focus group discussions said that cremation was considered only when there was a connection with the settled community, usually through marriage:

K: Me daddy's sister was cremated.

M: Again she was married to a settled person, but other than that, no, no Traveller whatsoever.

K: It was the same when our [] died, she was married to a settled man, she got cremated and me daddy was bewildered...

M: That's one thing that Travellers won't do, even consider. (Travellers)

Some participants in this study noted that walking behind the coffin or carrying it to the graveyard is still common practice:

M: You see what a Traveller does when a hearse goes up is that we all walk at the back straight to the graveyard.

L: If it was thunder, lightning they'd still do it, coz that's the tradition.

M: Some Travellers would drive but most walk.

Mg: Drive and then walk the rest of the way.

M: Walking shows more respect, like.

L: The way they take the coffin, the brothers and sisters and carry it up to the grave. (Travellers)

With Travellers, burial traditionally occurs where the mother or father's people are buried. Each family group or clan from a particular area will use undertakers, priests and churches known to those families (O'Brien 2000). Those taking part in this study also noted the tradition of being buried in your husband's family graveyard:

H: I'll have to go to [] that's where me husband and daughter's buried.

M: You have to go to your husband's burial ground. (Travellers)

In some cases the older people will be buried in the family plot but younger people may be buried in a more local cemetery.

M: Being in the area of [] now they'd all go to [], being the older ones would go where their mother or father was, but nearly all the others'd go to []. If there was any children they'd nearly go where they live but say the likes of the older one, like ole Nana, she'll want to go with her husband. (Traveller)

Okely (1983) notes that traditionally the body of the deceased was brought in an open coffin the day before the funeral from the undertakers and placed in a trailer at the camp where the deceased and family were living before the death. Sitting around the fire day and night, people would go at intervals to look at the corpse laid in the trailer. None of the women taking part in our focus group discussions referred to this custom. They did note how in most cases now the body stayed in the undertakers until the time of the funeral. There is often much touching and kissing of the deceased person and talking to the dead person aloud during Mass (O'Brien 2000). Travellers are renowned for the many wreaths and flowers that adorn the coffin and grave (O'Brien 2000). In our focus group discussions it was mentioned how in some cases the family will dig the grave, and fill it in after the coffin has been lowered. This is seen as something that the family must do and not strangers at the graveyard:

K: All the family does be there. They'd all dig in the grave, they wouldn't let other people do it, the workers, all the family dig in the grave they wouldn't let it open. (Traveller)

Rituals after death

Certain traditions and customs are practised after death. In some cases for a limited period (e.g. voluntary social exclusion, which can last a year), in other cases there may be rituals involving the grave and prayers over the first year and then yearly anniversaries after that. Practices such as grave tending and adorning would continue indefinitely. Many of the customs and rituals practised by Travellers after a death are similar to those practised by the settled community (Van Doorslaer and Keegan 2001). Some practices may be seen as more or less important or necessary, depending on the group.

One tradition the Travelling community is renowned for, however, is burning the trailer, caravan and/or belongings of the deceased. In many cultures the spirits of the dead are thought to act in the world of the living, to communicate with the living, and be present (more shortly after death than later) in the world of the living (Rosenblatt 1997). It follows, that some people believe that certain actions must take place to protect the people remaining from these spirits or to set the spirits free and on their way to the next life. Writing about the Travelling community, Okely (1983) notes that the funeral over, the personal possessions of the deceased must be destroyed as they are both polluted by and a magnet for the *mulo* (the ghost of the deceased). Clothing, bedding, personal crockery, work tools are broken up and burned on the perimeter of the camp; parts may be buried or dropped into deep water. O'Brien (2000) likewise reports how traditionally, the trailer and belongings would be burned to free the spirit of the dead person and to cope with the intense pain of remembering them. Some believe that burning possessions is a sign of how much the deceased was thought of

by their family (Carr 1992, McCann 1992, Reilly 1992). The extent to which property is destroyed can vary from family to family, often determined by their situation. For some burning all the belongings is not an option. Just the clothes might be burned and the bereaved family would move away from the place of death.

The Traveller women who took part in the group discussions talked at length about this tradition. Many felt this custom is dying out, due to practical and financial concerns. The practical implications of burning a trailer or leaving a house are fast negating the need to adhere to tradition. Many cannot afford to replace a trailer and feel that the need to follow that tradition has waned:

M2: That was years ago, say if one of your children or say your wife died, you'd usually burn the caravan, whatever was in it, but I don't think they really do it now though.

L: They don't do it now coz they can't afford it.

H: Well you know the beds and everything and things like they'd burn them up but I didn't do anything like that.

M2: One time when they died and they were in a house, the family would leave that house, no matter how long they were in it or if they owned it or whatever type of house it was, they wouldn't go back to that house. That was the old way of going and the older people always done that, like they burned the wagons and they'd leave that road because that'd be where they died, they'd go on and stay in a different part of the world. (Travellers)

Some participants agreed with the need to get rid of the caravan or trailer but the tradition of burning is declining. However, selling on a trailer will not necessarily rid the trailer of the ill feeling attached to it. Some Travellers may not buy a trailer if they know someone has died in it. Although seen as a tradition that is dying out and practised mainly by the more traditional Travelling families, it can still have significance to those who believe it is the appropriate thing to do:

My sister's caravan up there...me husband's brother took a heart attack there about two year ago and died in it and she never got rid of it or nothing and my husband has often said to her what's wrong with you, are you mad, why don't you get rid of the trailer. (Traveller)

With many Travellers now living in houses the notion of burning houses was mentioned. Many felt the sensible option was to leave the house for a time rather than destroy the property, especially when Traveller families in certain areas are waiting considerable time to be housed. Often the family will redecorate the house to create the illusion of a new place and to help adjust to life without a family member. Others mentioned how a priest often blessed houses after someone had died in them. It is possible that the redecoration and blessings are satisfactory alternatives to burning and leaving, as they aim to change the appearance of the house and protect against possible spirits.

Families would traditionally have moved on from the place they were living after the death occurred, likewise if they were on the road, or the person had died in a hospital, they would not go there again (McCann 1992).

Helleiner (2000) cites Gmelch (1977) and Okely (1983) who note that some Travellers prefer to move away from a place that had become 'too lonesome' after the

death of a close relative. As many Travellers are now more settled in halting sites and some in group housing, moving on is no longer such a common practice. In some cases if the circumstances of the death were particularly traumatic and remaining in the location proves too difficult for the family they will move on. They may burn or board up the residence before moving away. McDonagh and McCormack note that the recent Housing (Miscellaneous Provision) Bill 2002⁴ has significant ramifications for those who wish to move after a family bereavement, as re-locating is no longer an easy option for the Traveller community. They note that this Bill denies Travellers one of their coping mechanisms on the occasion of a family death (McDonagh and McCormack 2002). Participants in our study commented on the fact that the choice to leave and move elsewhere or even go back on the road has been affected by this new legislation:

They don't do that now because there's nowhere to go. They just kinda get rid of the caravan. (Traveller)

For many Travellers death means restricting all social events. This would include weddings and going out socially, even pastimes such as listening to the radio, and playing on the street with friends:

I remember when my husband died the priest thought I was mad. I wouldn't let the children look at television, I wouldn't put on the radio, for twelve months. They weren't able to go outside the door, they were like prisoners for twelve months. To show respect for him, they weren't allowed to go to the pictures or no place. (Traveller)

Some of the Traveller women felt that some customs such as wearing black were outdated and actually prolong the grief rather than helping the person. Some felt the traditions and practices varied between rural areas and urban areas, that those who lived in the country, especially older people, upheld many traditions that were dying out in the urban areas and not upheld by the new generations. This was also noted in a recent study of the settled community in relation to contemporary practices around death and dying in Ireland (Van Doorslaer and Keegan 2001).

Many Travellers practise the tradition of returning to the grave nine days later for prayers. O'Brien (2000) notes that on this day the Travelling community believes that the soul leaves the body. Most women who took part in our group discussions supported this. However, some women had never heard of the ninth day, highlighting once again how within the Traveller population there are differences in tradition and practices. Some Travellers will have a Mass said every month for the first year after the death and will gather at the grave but others will honour the first month or 'month's mind' after the person's death, the same as the settled population. As with settled Irish people, Travellers will often arrange for mourning cards to be printed and distributed to family and those that knew the deceased:

L: You get mourning cards and send them out a couple of months after the funeral.

M2: And give them out to all your friends and families, there's a photo and a very nice prayer and the age and what date they died on. (Travellers)

⁴ The Housing (Miscellaneous Provision) Bill 2002 makes trespass on land a criminal offence for the first time, with a new penalty of one month imprisonment and/or a fee of €3000. It will allow Gardai to arrest suspects without warrant, order people to move and remove property such as caravans without the knowledge of the owners

A year after the person dies, the headstone is erected and blessed, and some may have a Mass said beforehand. It is customary for as many people to gather for this ritual as did for the funeral. Feelings may be as raw as they were at the funeral. Prayers and poetry, and words of remembrance are often gathered and written in publications by the bereaved families (O'Brien 2000).

The blessing of the graves also known as Pattern or Cemetery Sunday is honoured by Travellers. This is a ritual practised by many settled people also. Most Travellers visit the grave often throughout the year and especially throughout November. Many will adorn the grave with statues, in some cases brought from Lourdes⁵ (O'Brien 2000). Whereas for settled society the place of birth is the primary marker in terms of personal identity, for Travellers the grave is the ultimate marker (Okely 1983). Around Ireland there are many graveyards that are known as Traveller graveyards. These are known for their well-attended graves, elaborately decorated with statues and large expensive gravestones, and fresh flowers, wreaths and colourful ornaments. Travelling families will generally mark significant anniversaries of the death by buying additional adornments for the grave. Other decorations are often added at Christmas and birthdays although family members will tend the grave throughout the year (Williams 2003).

The women in our focus groups talked about the importance of the graves. Some alluded to the competition which exists among Travellers in relation to putting up elaborate and expensive grave decorations. Although the women themselves thought this unnecessary and in some cases to the detriment of their families, they did admit it was becoming common. Another tradition, although it is not exclusive to Travellers, is having a photograph of the deceased on the headstone. Visiting the grave on a regular basis is seen as very important to Travellers. Those that took part in the discussions mentioned how important it was to visit regularly and tend the grave, to keep it tidy and to pay respects to the deceased. It was also seen as important to be buried in a graveyard close to remaining family so that they could come to visit regularly. The tradition of being buried where your family originates from is waning for this reason.

Those taking part in the focus groups reflected on how things had changed over the years. Many old customs were not seen as appropriate any more and new traditions were coming into vogue, such as singing the favourite song of the deceased:

Mg: They're doing that a lot now you know, they're singing the favourite song of the person over the grave.

A: Years ago they didn't do that. (Travellers)

There are often major generational differences in dealing with death. Typically it is the older generation that seems more observant of the rituals and more dedicated to the cultural meanings and emotional forms that have been dominant in the culture (Rosenblatt 1997). The younger generation of Travellers, especially those who may have been living in one place for most of their lives, have adopted some of the 'settled' ways of doing things. This has occurred naturally through exposure to television and mixing with 'settled' peers at school, on courses and at work. It is also

⁵ Lourdes, in the south of France is an important place of pilgrimage for Roman Catholics.

possible that this younger generation would not have been as exposed to the rituals and activities to the same extent as their elders and therefore not have the same level of adherence to the traditional Traveller ways. Rosenblatt (1997) emphasises that outsiders who may want to understand and help people from small-scale societies (including Travellers) must be sensitive to the possibility of different needs, expectations, standards and practices in different generations.

Bereavement support

Bereavement support was discussed with those that took part in the study. Most Travellers felt that the support from the family was enough and that it would be rare to seek support elsewhere, especially from a bereavement counsellor. The lack of use of existing bereavement services was noted by some service providers and is explored in the section relating to use of services. Some women mentioned how the priest was an important support for the bereaved family:

P: Yeah, a lot of Travellers talk to priests.

K: A lot of the priests would come to the Travellers. If they know ya, they'll come.

L: They'd probably spend a few days coming back and forward to you the whole time. (Travellers)

In summary

This chapter presented some of the many varying practices and customs that the Travelling community observes around the times of serious illness, dying, death and bereavement. It presents findings from both the available literature and the data collected as part of this study. Although some of the rituals and traditions have different emphasis and some have been adapted and altered to suit the needs and values of Travellers, the similarities with the rituals practised by the settled community remain notable. This can only be expected when sharing the same country for centuries. However, these similarities do not detract from the notion that cultural difference needs to be considered when taking into account how people behave at times of death and dying and that within different cultural groups practices will vary to different degrees. This difference must be valued and respected.

Travellers and palliative care

This chapter presents Travellers' ideas and views on cancer, dying and death, and their use and opinions of palliative care services. Throughout the focus group discussions Travellers' knowledge of the services was considered, as were their ideas and assumptions about the services and their use of palliative care.

Cancer and dying

For non-Travellers to understand how those from the Travelling community react and behave at this time, it is important to know the underlying assumptions and deeply embedded beliefs. Ideas and beliefs relating to death and dying directly influence people's behaviour around these life events. What is seen as appropriate and correct behaviour at such times is culturally embedded. Different cultures define the meaning of death or its causes in different ways. Death can be defined as a gift from the gods, or as a result of a malevolent act, or as caused by someone, for example someone who may have cursed the deceased from a distance (Rosenblatt 1997). Traditionally, Travellers would have believed in the power of curses, especially those of a widow; however, few would believe in the power of curses now (Rattigan 1992). The focus group participants did not refer to curses that could cause death, although there was a sense of superstition and unease around the whole topic of death and dying. In the methods section earlier it was noted how some Travellers did not want to visit the hospice for fear of carrying a sense of death back to their community. This alludes to a notion that death, in their eyes, can be caused by matters other than medical or accidental. In the group discussion several mentioned that being in institutions such as hospitals and homes could hasten a person's death:

P: She was only a couple of months in the hospital when she died. Wasn't that weird.

L: You see that's what I'm saying you don't know what goes on in the hospital when you're not around.

K: But the hospital killed that old woman, she'd be living yet. (Travellers)

Participants had a wide range of experiences of death but it was clear that they felt uncomfortable talking about cancer, dying and death. Many needed encouragement to take part in the discussions, and they made it clear that Travellers would not habitually sit and discuss such topics; they tend to keep personal things to themselves and their close family. The groups talked of the difficulty of talking openly about an illness or a situation where someone is dying. They said how they found it hard when medical people or settled people discuss details of an illness, and that they preferred not to know the details:

L: I'd let them talk if they wanted to talk but I wouldn't get involved in a whole conversation.

B: You wouldn't get personal with the details, the way [settled] people do.

N: You know what's wrong so there's no need to talk about it. (Travellers)

There was a fear of talking about cancer, saying the word itself appeared difficult for many Traveller participants. In the focus groups people regularly blessed themselves

as we talked about cancer. It was as if they would be exposing themselves to a risk by even uttering the word:

H: They wouldn't hardly talk about it sure. They'd say such a one is dying but they won't say what from they wouldn't dare say that word.

B: Yeah, we don't even say that word, they won't even say what it is, they just say the bad complaint and touch the table.

H: Or bless themselves.

H: You get a shiver over your body when you hear that word. I get a shiver down me neck and back and arms. (Travellers)

This supports the issue discussed in the methodology section in relation to inviting groups to visit the hospice and the fears that exist for Travellers around the notion of inviting death into their homes by talking about it or, engaging in an activity that involves death or dying to any extent, even if for educational purposes.

One participant noted how from her own experience she felt that settled people could talk about cancer with an ease that she as a Traveller found both surprising and upsetting:

What frightened me even more was...how openly the people were talking about it, the settled people...what kind of treatment that the child was after having and how it affected him and I said to myself 'they have no feelings, they must be numb people', because they were talking about it so casual, but they just found it so easy to talk about it... I couldn't cope with it, I had to get up and walk out, they just had a different way of communicating than I would...(Traveller)

Many participants talked of the fear of cancer among Travellers. The word itself has the power to '*frighten the life out of ya*'. Some had examples of family member reactions:

My grandmother got skin cancer in her leg and I remember the day it was diagnosed in the hospital and the doctor told her that it was just a simple operation and it could be removed, but the minute she heard the word she just fell completely to pieces, she started shaking, she automatically thought like that that was it...that's not what she died from in the end but... the minute she heard the word cancer she just fell apart. (Traveller)

Some Travellers were aware that some types of cancer could be treated and the importance of early detection, but this did not detract from the fear of such a diagnosis. Other participants talked about cures from healing people but it was accepted that healers usually offered cures for only skin cancer and not internal cancer. There was a sense that some Travellers were aware that the diagnosis of cancer did not mean certain death. Some talked about treatments available that could cure or prolong life. There was a notable difference between men and women going for check-ups. The groups felt that men were reluctant to get their health check-ups and would often suffer rather than go for a check-up or tests, and that men, more than women, have a real fear of a cancer diagnosis. Women are, according to those attending the focus groups, better at check-ups and regularly attending general health services. Many Travellers in the group discussions talked about the frequency of late diagnosis of cancer and the late presentation that they attributed to the fear of the

diagnosis. Others talked about wanting to hide the fact that they may have cancer, out of fear of the disease or of having to leave their families and go into institutional care:

L: They want to hide it, a lot of Travellers, I don't know if anyone else agrees with me, but a lot of Travelling people hides it.

H: They hide it till the end, sure that's what happens to them.

B: There's a fear of being put into a home. (Travellers)

Some thought that an actual diagnosis of cancer would speed up the dying process, that once the person was aware that they had cancer they would give up hope and die sooner.

Hope and fear

The concept of hope was raised frequently in the focus group discussions with Travellers. During ill health, hope is seen as crucial to give the patient a purpose for getting better and as support and comfort for the family. Once a person gives up hope they are resigning themselves to dying and Travellers find this hard to do. Travellers would prefer not to talk about cancer as it would result in a person giving up hope of living:

A: I think when they find out they die quicker from the worry.

L: They give up hope probably.

K: You'd say I have nothing to live for, you'd give up doing what you were always doing. (Travellers)

One service provider commented on the strong sense of hope Travellers have, sometimes even after a person had died:

On two occasions I have been with a family and say the mother or father has died an hour before hand, and they talk at that time of the hope and they are just waiting to see if they are really dead. Apparently from speaking to other people that's quite ordinary and normal for Travellers to feel like that. But for settled people, okay you might be shocked that the person has died and you might wish that they were still alive but you wouldn't really believe or hope that they were going to waken up. But this hope ...it's a very spiritual idea that there's definitely a higher being. (Social Worker)

The fear of cancer may result in people fearing places that are associated with cancer care and treatment, and avoiding treatment:

M: She wouldn't go to St Luke's because St Luke's was a terrifying name to her and she says sure once you go to St Luke's you're incurable, you wouldn't be coming out.

K: You would hear of a Traveller attending it and you would God bless us and save us know what they were going for and you knew what the hospital was for and I think that's what frightened Travellers. (Travellers)

Place of death

Discussing dying led to discussion about Travellers preferred place to die. Most of the Travellers who took part in this study thought that most Travellers died in hospital but would actually have preferred to die at home. Many expressed a desire to die at home and many felt this was traditionally where Travellers would choose to die:

P: Nowadays they are dying in the hospital, years ago say my grandfather he died in the trailer.

K: That was his wishes he wanted to die at home. (Travellers)

Participants thought there were definite benefits to dying at home. There would be no restrictions on the number of visitors or any fear of disturbing other patients. Occasionally, a person may want to die at home, and the family may want them to, but they may have to go to hospital for medical reasons or because the family can no longer care for the dying person adequately at home. Although it was appreciated how difficult it could be to mind a dying person at home, it was felt this was still the preferred option. Help in the form of home care was seen as a way to keep the dying at home and thus fulfilling their wishes, which was seen as important:

It would be heart breaking but you see I'd rather have it because they'd still be at home and you'd know that this was the way they wanted it to be ...and the care is coming to them and they could stay for hour after hour if they wanted to once I know that they are where they want to be, once they are happy in their mind. (Traveller)

Various circumstances were discussed in which participants felt it would be preferable to die away from the family home: if Travellers felt they would be a burden on their family then they would prefer to be in a hospital or hospice; another reason stems from the tradition of burning the trailer or leaving a house after someone has died in it. Moreover, a person and or their families may feel more comfortable dying in a hospital and hospitals were seen as the best place to receive the most complete medical care and attention:

They have the tablets there, the equipment in the hospitals or them places that you are talking about. If anything is going to happen to them, they can be looked after right properly. (Traveller)

Although opinions varied there was a clear sense that either home or general hospital were the two options. All Travellers taking part in the study agreed that hospice would be a last option in terms of choosing a place to die. The sense was that at least at home or in hospital there was still sense of hope:

Yeah when they are in an ordinary hospital they think they're coming home, they think they are getting better and when they are at home sometimes they think they are getting better, it depends what state of mind they are in. But when they are up there [the hospice] they think there's no chance, that's it. (Traveller)

Experiences of palliative care

Throughout the group discussions with Travellers a certain level of confusion always arose in relation to palliative care and on occasion to the health services in general. Most Travellers would refer to doctors and nurses but would not differentiate according to specialities within the health services. Therefore, the concepts of a palliative care consultant or specialist palliative care nurses were not easily understood unless a person had had direct personal experience and even then they might be referred to as the cancer doctor or cancer nurse. Likewise, most participants found terminology confusing and many did not differentiate between hospital, hospice, nursing home or convalescent home. One participant referred to the hospice as 'them places that you are talking about'. In most cases, groups were primed in

advance by course leaders or co-ordinators about our research and the topic for discussion, and then palliative care was usually presented as hospice care. Throughout the groups there was no mention of the concept of palliative care within a hospital setting or a hospice homecare service. These obstacles arose when trying to ascertain participants knowledge about the services.

A wide variety of views were presented when participants were asked about palliative care and hospice services. Some participants had clearly not heard the term hospice before, although they may have been aware of the service, and some participants had learnt about hospices through personal experience:

M: We hadn't any clue of that – hospice is it – in Raheny until my sister was in it.

Mg: I wouldn't of known except I went to visit her. (Travellers)

Some Travellers referred to people they had known who had used a hospice, but the same few examples were mentioned again and again, many people being related to those few who had died in a hospice. Indeed, few Travellers have used the hospice service to date. As the discussion developed participants would often ask each other or the researcher for clarity:

L: How many do they hold for, how many does be in them? You'd probably have to have an appointment.

M2: Like a hospice, would that be built like a hospital with loads of rooms or would it just be a small little place.

Mg: It's like a hospital. They're more considerate, more kinder.

H: Like the John of God's⁶ inside and it's beautiful outside.

A: More homely, like you have your family around you.

Mg: More homely where you'd get the best of everything.

H: It's really bright inside it's lovely.

A: You can have a few drinks if the person feels like drinking. What ever they do in the hospital it's no smoking or drinking.

Mg: It's top class treatment. (Travellers)

As the above illustrates, there are varying views about what a hospice is and the service it provides but most examples are about the building and the level of care and not about hospice as care for terminally ill people, or about palliative care as comprehensive care for those with progressive fatal illness.

Once the discussion was steered towards the purpose of palliative care in general and more specifically the hospice, participants offered their opinions on the idea of hospice care and a family member receiving care there. The majority were clear that they would not choose to send a dying family member to the hospice, and some were more emphatic than others:

Personally I wouldn't like to go in to one and if I was dying this minute I still wouldn't like to go into one. And I wouldn't send me mother or father there eitherno I'd rather have them at home. (Traveller)

Participants were quick to say what a lovely place the hospice was, focussing on the caring staff people and the pleasant facilities:

⁶ St. John of God's Psychiatric Hospital

It'd be the last resort anyway trying to put someone in a place like that but it was so nice a place because anyone that went to see that person in the hospice said it was a beautiful place. (Traveller)

It was a spotless beautiful comfortable place, it was friendly when you walked in. It was like a hotel it was fabulous and they give you your last, every good thing they give it to you before you die. They talk to you, play music, you can do what you want, get up and walk around. Beautiful, like a hotel, excellent. (Traveller)

The fact that large numbers of Travellers could come into the hospice without it being a problem was seen as very positive:

I seen a good few people going in and out and they don't say nothing to ya. They're good people there you know. (Traveller)

Reservations about the use of hospice services related to the hope that Travellers maintain in relation to the sick and dying, hope that the dying person may recover. Hospices represent a loss of hope:

M: You put them in there, that's it, you're putting them there to die, and there doesn't be any more hope for them.

K: I think they just give up hope the minute they get in there. (Travellers)

Hope is an essential and vital part of Traveller life, and loss of hope was associated with a quick death.

Participants who had some experience or knowledge about hospice care compared their experiences with the care received in general hospitals. Interestingly their impression of hospices was more favourable than their impressions of hospital:

I went there about two times, I went to see her when she died, in the mortuary, they were very good. There was nothing they didn't need, they were very good, and very kind with them 24 hours you know what I mean. Whereas in the hospital you're dumped in a bed in the corner, you're pining away, you're dying away. (Traveller)

Others agreed that the hospice was not to be feared like the hospital, that it was more comfortable and that the staff were very nice, based on their experiences of both. This appears to contradict statements that a hospice is the last place they would choose for treatment.

Some participants had experience of what were probably palliative care services, although they do not refer to these services by that label. It is possible also that they were local public health nurses rather than hospice homecare nurses or oncology consultants rather than palliative care consultants.

Most of the palliative care discussion focussed on the hospice unit and hospice homecare services. Significantly many were unaware of the hospice homecare services:

Maybe if a person is sick in a caravan would they come and do that there or does it have to be in the hospital? (Traveller)

Some participants had direct experience of hospice homecare nurses and fully accepted their role and value to the dying person and their families:

K: It was great like she could do things that we couldn't do for him.

L: Sure you'd be afraid to do anything for them, coz you wouldn't know what you're doing.

K: Sure you can't go around a sick person, but she'd know how to care for him and look after him you know. I thought she was brilliant when she was out that time. (Travellers)

Those who did not have direct experience of hospice homecare agreed it would be a good idea in theory to have someone coming to the home especially if they were helping out with pain relief. Most were still cautious about letting someone into the home, however, and saw the family and not strangers as key carers of the sick.

Asked how they had heard about palliative and hospice care, the travellers said it was through watching television, listening to the radio or from training courses that they had taken part in:

Over the years, now through education and watching telly and things like that, but I've never actually known anyone that was in one, anyone of me family that was in a hospice... (Traveller)

Some were made aware of the hospice service by the hospital where the sick family member was a patient. Many participants presumed that they as Travellers would not be entitled to the services. Some questioned whether you would have to pay for it. Others thought you were reliant on the kindness of healthcare professionals to be referred:

And then you are put to a hospice if the doctor is good enough to send you there and kind enough. (Traveller)

Some participants spoke of the services they had experienced. One woman said how well a family member had been treated:

To me the reception that she got in that hospice of the nurses was absolutely out of this world, which all the patients get the same treatment of them, looked after the same way. They stood by her in everyway. (Traveller)

Another woman, talking about the same example, explained why they had felt the service was so good: the place had accepted the volume of visitors and this had not been a problem; the doctor had treated them with respect, had explained the situation in a manner they could understand and in a private area away from others. Also mentioned were the good facilities which are seen as important in terms of receiving good quality care.

Many participants voiced the fear that Travellers have of institutional care including hospitals, homes and hospice. They fear being away from their families when they die, and would prefer to be with the family and ideally at home. It was noted that institutional care can be lonely, for those there and for those visiting. One woman wondered if her relative would have lived longer had she been at home:

She probably would of lived longer on the site coz she was used to the liveliness, she was used to her home and doing everything her own way. The children was always in visiting her. (Traveller)

When asked about bereavement support there were varied responses. Some were not aware of the concept; others had heard of someone in the Travelling community who had availed of the service:

Facilitator: Anyone here ever go to a bereavement group, or have you ever heard of that?

A: No

Ma: What is that, it's a funeral thing, talking about the funeral.

Mg: What way would that help you?)

L: I heard of it.

H: Yeah, they do help. Yeah someone went there and they were all talking of how it happened and you know they all sits around a table and they talk of who died belonging to them, it was ... was it?

L: Yeah, she said she found it very good. She told me she found it very good. She said to me she'd never have coped if she hadn't have gone to them.

(Travellers)

Going to a bereavement group to talk about the death of a family member or close friend was not seen as an appropriate option for Travellers, although, it was accepted that many needed help with coping with a death. They said that they would prefer to talk one-to-one with a person who was not a stranger, possibly a family member or a friend:

L: No I'd rather go to my sister or somebody.

Facilitator: You'd rather talk to someone you know rather than a stranger?

L: Yeah, you'd feel like they'd know the person that you're talking about. It's hard to talk to someone that don't even know the person that died or the situation or the circumstances.

P: Yeah they couldn't know your feelings.

L: Yeah if you're going to someone with the same feeling you are able to relate more to them.

P: I think you open up more to your family than a stranger, anyway.

(Travellers)

Some were very clear that talking with a counsellor would not help you if you were bereaved. Others agreed that talking it out with a friend, possibly from the settled community, was a good idea, especially when your family may not be able or willing to hear about it anymore. It was mentioned that in some cases the local priest would call by and offer support. Talking to a priest appears to provide an opportunity to express emotions in a safe way:

M1: When my father died, my mother just brought us down to see Father ...and he brought us into the room, one by one, that was very good. He was a priest.

L: Yeah when my grandmother died I went to the priest as well. It's the same as counselling really. (Travellers)

In Summary

This chapter considered how Travellers view dying and death. Their beliefs about cause of death, dealing with cancer, the notion of prevailing hope and their preference for where to die can directly impact on their interaction with palliative care services. We also explored with the Traveller women in the focus group discussions, experiences and opinions about palliative care and hospice care. When assessing knowledge and understanding of palliative care services most participants talked about the hospice unit and hospice homecare. There was little reference to the philosophy of palliative care (i.e. caring for the physical, emotional and spiritual aspect of a patient with a progressive fatal illness). Palliative care is another health service that Travellers know little about and, due to the fact that it concerns people suffering from cancer, and recognition that an illness is fatal, it is something that they fear. Although those with experience praised the hospice in terms of staff and facilities, access for large numbers of visitors, and opportunities to discuss things with a doctor in private, most participants were clear that it is a place they fear and they would see it as a last resort to have a family member die there. Hospice homecare was acceptable to deliver pain relief and nursing care but not emotional support. The immediate family, not strangers provides emotional support at this stage of an illness. There is a prevailing fear of cancer, resulting in late presentation with symptoms. Men more than women are reluctant to have any symptoms or pains checked out for fear of negative outcomes. By and large Travellers still fear cancer to the extent that they prefer not to talk about it. When mentioning it, they will bless themselves to protect themselves from it and remain uncomfortable with any discussion relating to illness, dying and death.

Barriers to palliative care services

We surveyed palliative care professionals working in the ERHA to establish the contact they had with the Travelling community. The survey also explored the concerns palliative care staff had in delivering services to the Travelling community, and the barriers to service use and access for Travellers as perceived by service providers.

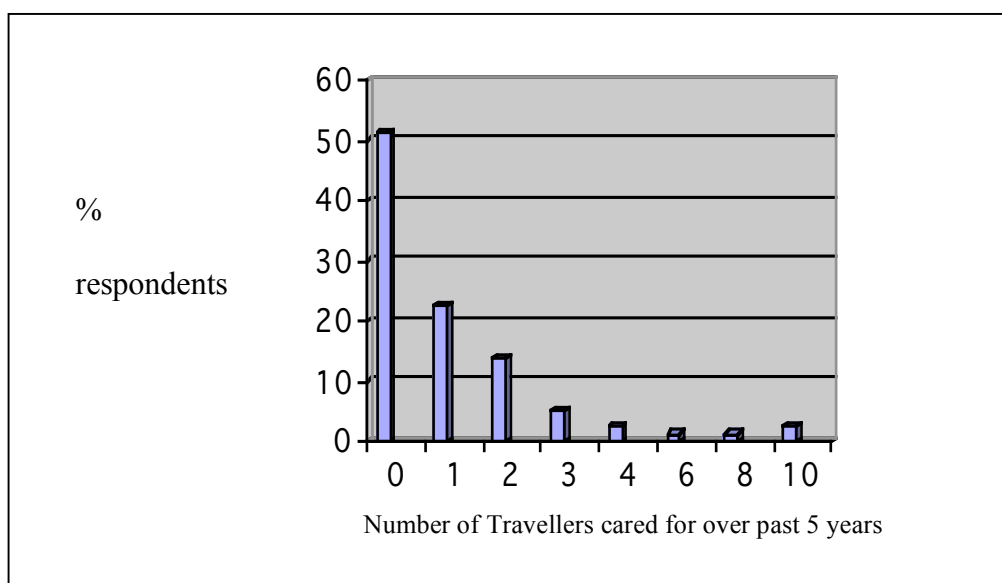
A short self-report questionnaire was distributed to palliative care staff in a variety of ERHA services. A total of 215 questionnaires were distributed, and 81 completed questionnaires were returned (response-rate of 38%). Completed questionnaires were received from staff in eight specialist palliative care services.

Respondents were asked first if they routinely record the ethnic origin of their patients. Almost two-thirds (61%) indicated that they do not routinely do so. (One respondent did not answer this question). Staff were also asked if they routinely record membership of the Travelling community. Again the majority (over 66%) indicated that they do not; five respondents did not answer this question.

Respondents were then asked how many members of the Travelling community they had cared for in a) the past 12 months and b) the past five years. In the last year 86% of respondents had not cared for any member of the Travelling community, 10% had cared for eight, and 4% (three respondents) had cared for two Travellers .

During the past five years, respondents cared for, on average, one Traveller, with two respondents caring for 10. Just over half (51%) of respondents did not care for any Travellers over the five years, while 22% cared for only one. (See: Figure 2)

Figure 2: No. of Travellers cared for by respondents over the past five years



Respondents were asked if staff training or education about Travellers was available to them in their place of work. The vast majority (89%) of respondents indicated that

no such training was available. A related item enquired whether respondents had *ever* received any training or education about Travellers. Once again the majority (85%) indicated that they had received none, with just 15% reporting that they had received some form of education or training. Those who said yes were asked to elaborate on the nature of it, and 13 respondents answered this open-ended question. Results indicated a diversity of experiences, both in terms of the extent and nature of the training received. Most of the training appeared to be a single lecture or talk on the topic, sometimes augmented by the respondent reading additional material. (Table 3) In several instances insufficient information was provided to understand the nature of the training received (e.g. ‘in-service’). In addition, it appears that much of the training related to Travellers and health in general, rather than to palliative care services for members of the Travelling community or issues relating to death and dying.

Table 3: Respondent education/ training received in relation to Travellers.

Type of education	No:
Conference, study day or course	6
Special training	4
Reading	2
Lecture or reading	1
Total	13

Barriers to service provision for Travellers

Previous surveys on Traveller health have identified several barriers to the provision of services for members of the community. These barriers were listed in the present survey, and respondents were asked to indicate the extent to which they felt each of the barriers presented a problem in terms of delivery of care to Travellers. Respondents could choose from three possible responses: ‘*not a problem*’; ‘*a serious problem*’ or ‘*don’t know*’. Responses are presented in Table 4.

Table 4: Barriers to delivery of care to Travellers.

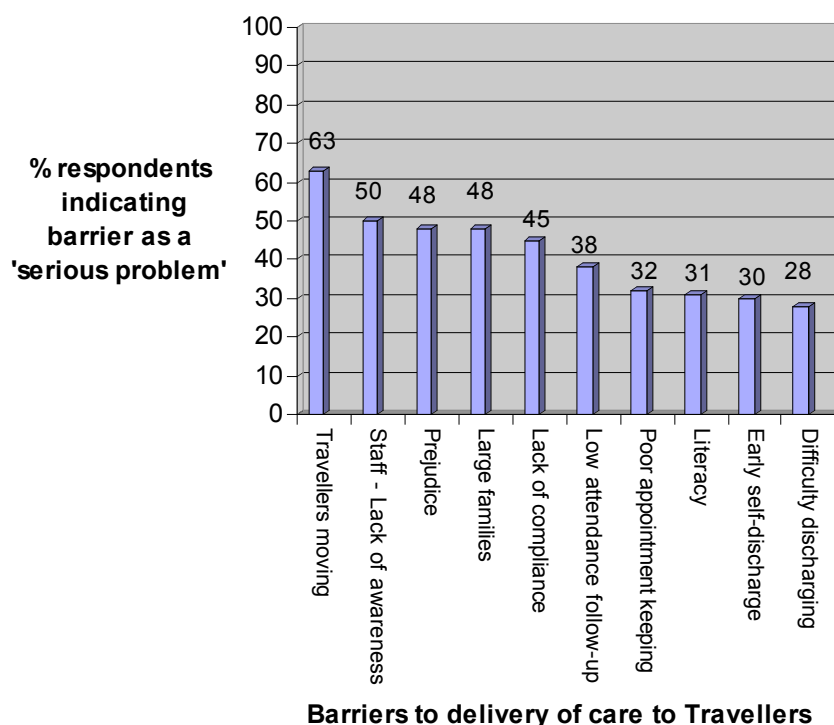
Barrier to service provision	Not a problem (%)	A serious problem (%)	Don't know (%)
Low levels of literacy of Travellers	44%	31%	26%
Lack of awareness of different Travellers beliefs & culture	26%	50%	23%
Prejudice against Travellers from the public & service providers	31%	48%	22%
Travellers moving from place to place affecting continuity of care	11%	63%	25%
Large Traveller families involved, leading to over-crowding	30%	48%	23%
Low attendance for follow-up care by Travellers	19%	37%	41%
Difficulty in discharging Traveller patients from hospital due to poor accommodation and limited hygiene facilities.	28%	28%	43%
Early self-discharge by Travellers from hospital	28%	30%	42%
Lack of compliance	16%	45%	39%

Note: percentages do not total 100% for each item, as some responses, such as 'not applicable', are not include.

Results in Table 4 show that many respondents did not know whether certain factors were a problem in terms of delivery of care to Travellers. Presumably this is due to the low numbers of Travellers being treated by staff – as noted earlier over 83% of respondents have not cared for anyone from the Travelling community in the past 12 months.

From the number of respondents who identified barriers as posing ‘a serious problem,’ we can rank the barriers in order, from those most often identified as being a serious problem, to those identified least often (Figure 3).

Figure 3: Percentage of respondents rating barriers to service provision as a 'serious problem'.



The barrier to delivery of care most often identified by respondents as being a serious problem was the fact that Travellers move from place to place, and the resultant repercussions for continuity of care. Lack of awareness by staff of the different beliefs and culture held by Travellers, as well as prejudice against Travellers from the public and service providers, were the second and third most commonly identified barriers, with 50% and 48% of respondents identifying these respectively. 30% of respondents felt that early self-discharge by Travellers from hospital was a serious problem, while 28% cited difficulties in discharging Traveller patients from hospital due to poor home accommodation and limited hygiene facilities.

Finally, respondents were asked to record any experiences with Travellers which they felt might be relevant to the provision of specialist palliative care services. Twenty-one respondents replied to this item, and several themes emerged from the responses given. These can be broadly grouped as:

- Experiences regarding the behaviour and needs of **Travellers** within a palliative care setting.
- The needs of **health care providers** working with members of the Travelling community within a palliative care setting.

The most frequently cited experience regarding Traveller behaviour was the large family groups that accompany the patient in hospital. Large families were viewed in

both a positive and negative light: one respondent indicated that *'large, supportive families are often an advantage'*, with others reporting that many Travellers are *'very attentive to the care of their relatives'* and generally *'supportive to their ill family member'*. Another noted that *'family visitation is very important...no matter how large the numbers'*. However, large family groups were also viewed as causing overcrowding. This was identified as a problem *'for an in-patient institution where other patient needs and needs of families need to be met'*. While one respondent found that problems with overcrowding were *'certainly managed appropriately'*, others highlighted noise and the fact that *'other patients are frightened of travellers as they speak so loudly. Boundaries need to be set prior to admission and adhered to.'*

Other behaviours and needs of Travellers within the palliative care setting were also identified. One respondent had cared for members of the Travelling community in a radiotherapy rather than palliative care setting, and identified *'a huge need for chaplaincy input as religion was a major source of comfort'*. Another respondent identified feelings of isolation which can affect Travellers, reporting that *'they feel imprisoned if isolated in a single room. The walls close in on them, and they feel rejected and isolated by staff and the other patients'*. One health care provider encountered, in a particular case, a *'desperate desire on behalf of the patient to be away from the hospice and independent although his physical condition did not permit this. Staff invested huge amounts of time in caring for the patient and extended family around this challenging issue. This was highly stressful at times'*. One respondent identified literacy as a difficulty, but this was in the context of an acute surgical ward, where problems arose with consent forms.

One respondent voiced concern about large Traveller families and associated safety implications for nursing staff in the Travellers' home (rather than in the hospice), expressing *'reservations about putting a night nurse into the Travellers' home at the end stage because of large Traveller families and extended families gathering at this time which can lead to a very volatile situation'*. Otherwise, opinions tended to revolve around the need to respect members of the Travelling community and to *'treat them as people who have a right to be cared for with dignity'*. One respondent indicated that it is *'our attitudes and prejudice against Travellers that affect care for them'*, and suggested that there is a need to *'respect their culture and beliefs even if we don't approve of them'*. Respondents indicated a clear need for further education and training regarding the culture and beliefs of members of the Travelling community: *'formal education on the Travelling community, their beliefs and culture is extremely important for staff if we are to provide adequately for their care'*. Another respondent expressed interest in *'getting to know the spiritual and cultural beliefs and customs of Travelling community'*, while a second stressed *'need to acknowledge and respect cultural differences e.g. place of death. Need to be aware of Traveller wariness of hospice and what it signifies.'* This theme is summed up in the following remark from one palliative care provider: *'Particular problems around Travellers are similar to issues and problems around any ethnic group. One of the challenges which is part of the basic philosophy of 'palliative care' is facilitating differences, caring for people as they are, not how we feel they should be, so the issue to be addressed is cultural difference.'*

Experience and attitudes

The service providers had a limited experience of dealing with Travellers on a professional basis. Those who had treated and cared for Travellers spoke of their positive experiences. There was a sense that the Travellers were grateful and appreciative of the care given. Some professionals who had no prior experience of caring for Travellers, expressed an interest and curiosity about caring for Travellers.

Throughout the interviews and group discussions, the participants in general were open about their lack of knowledge about this ethnic minority group and in some cases embarrassed about how little they knew. Many recognised that if they had more experience of caring for Travellers, they would learn more about Travellers and their culture. Some recognised that their ideas were largely based on popular stereotypes of Travellers as portrayed by the media and popular folklore, which included negative stereotypes about violence and poor levels of literacy. The greater opportunities available to younger travellers were recognised.

The topic of cultural diversity was often raised. The palliative care professionals were aware of a range of issues resulting from cultural difference, and they talked of the biases that arise, the problems with communicating and the impact of Ireland becoming a multi-cultural society with the arrival of non-national workers and refugees. All these will impact on palliative care services. The individualised, patient-focused philosophy of palliative care, means services should be flexible enough to meet the needs of patients and their families. It was suggested that other non-national cultures are seen as more 'exotic' and 'exciting' in comparison to our own almost invisible ethnic minority group, the Travellers. Some service providers talked of the dangers of imposing their views and cultural ideals on to their patients, and how the initial reaction of palliative care staff may be to try to change how the Travellers lived to match the standards and ideals of the staff without realising that ways of living are culture bound.

It was suggested that Travellers might have different views about dying from cancer and different perceptions of the need for palliative care. A service provider also has to appreciate different abilities to comprehend many aspects of the medical world. This can present a challenge if the service provider lacks information about how best to approach things with Travellers and what areas of treatment may present problems. The lack of formal education among Travellers, especially older Travellers was likewise considered to be a problem.

Caring for and treating members of a different culture can be challenging, especially when patients are an indigenous ethnic minority group such as Travellers in Ireland. Travellers over the centuries have adopted many of the ways of settled people whilst fighting to keep their own identity and culture. There are many issues that relate to Traveller rituals and traditions which service providers need to be aware of and incorporate into their view of caring for Travellers. What can be very challenging for service providers is when Traveller groups see rules and regulations enforced by settled bodies and institutions as not applicable. One service provider recounted an occasion when this occurred, and the upset and frustration caused by the clash of establishment and cultural difference:

I remember when the little girl died, it was quite quick and there was a lot of people from the Travelling community who came up from where she was from and because she had Hep C (Hepatitis C) she had to be put in a body bag which was very traumatic for the family, it really was difficult and they had been told about that before but they just hadn't heard it and I remember all these Hiace vans parked outside and the registrar nearly being assaulted because he was insisting that she had to go into a body bag and there was no reasoning and as far as they were concerned they didn't have to abide by this rule, so it was very difficult. (Palliative medicine consultant)

One barrier may lie in how Travellers view services in terms of their own cultural norms. Travellers, it was proposed, may see hospice care as abandoning the person not helping them.

Others mentioned how religious difference can also raise issues. On occasion providers may go to great lengths to accommodate a patient with a different religious background while a patient with a familiar religion may not receive such special treatment. Likewise, it was suggested that palliative care professionals may inform themselves about other cultures and religions and the appropriate ways to help these patients but will not have read up on the Travelling community. Now however, training and information days in some places are preparing staff for new and different cultural ways of viewing death and dying.

Culturally appropriate services – issues for professionals

It was suggested that the homecare service may be most appropriate in addressing the fear that Travellers talked about in relation to the hospice. Homecare services support patients in their desire to stay at home. More palliative care professionals thought travellers would prefer to die at home. While admitting their lack of experience or knowledge of Traveller housing and accommodation, some service providers felt that the possible lack of facilities on-site (such as sanitary facilities, running water, etc.) may present problems for service delivery. Others wondered about the trailer in which a Traveller patient may live, and were curious if there would be such things as heating for the patients. In discussion, others realised that issues around living space would not be exclusive to Travellers and that service providers could improvise. In terms of the practicalities of delivering a homecare service, it was noted that one of the issues is simply keeping contact with patients. It was felt that this may be more of a problem with Travellers than with the settled community.

Others wondered if Travellers would feel comfortable using in-patient services. Service providers were also concerned that being in a building or an institution may not be acceptable to Travellers. Others mentioned how Travellers may have an issue with institutional-based care on account of their nomadic practices, although they were unsure to what extent Travellers still travelled and whether having to stay in one place would present problems for them. Some felt that perhaps a hospice and its requirements in terms of compliance with medication and conforming to the rules may not fit in with a Traveller's viewpoint or way of being.

Some mentioned how the hospice setting, with its good facilities and comfortable surroundings may not be the welcoming places intended. In the focus groups with Travellers, one participant referred to the hospice as *'like a hotel'*. When this was

mentioned to one of the service providers the response was that preferably the hospice should not be seen as a hotel because people may not be comfortable with that idea. Palliative care professionals would like hospices to be seen as homely, but noted that some settled people also found the luxury of hospices unacceptable. The point needs to be made that for many Travellers the idea of living, even only for a few weeks, in a building and not a trailer would be foreign and alienating.

There are mixed views among service providers about the ability of hospitals and hospices to cope with the number of visitors and family that accompany Traveller patients. Some service providers thought that hospices, being small may not be able to cope with large numbers of visitors, whereas others thought that the flexibility of hospices made visiting and accompaniment by extended family easier to deal with. Crowds could be an issue in an institution – a hospice or hospital, or for care at home. Palliative care professionals, including night nurses, may feel insecure on a site or in a house where there are large crowds. It was recognised that in most cases service providers are dealing with a large group of people when trying to communicate with a Traveller family. In some cases it can be hard to identify whom you should be talking to. The possible advantage of having an identified key person with whom to communicate was discussed.

In discussions the palliative medicine out-patient clinic in St Luke's Hospital⁷ was suggested as an all round one-stop-shop that could address the patients' issues quickly and efficiently, which may appeal to Travellers as well as the settled population. The question was asked, are any of the services available under the umbrella of palliative care actually appropriate for the Travelling community. Most of the palliative service professional participants agreed that service use had to be based on choice. Patients need to feel free to use or not to use the services according to their own ideals and beliefs. This applies equally to Travellers and to settled people. Palliative care professionals recognise the value of the service they provide but what they provide may not be recognised by others as necessary or valuable. Hospice day care was not specifically mentioned in the discussions with palliative care professionals.

Lack of knowledge

A lack of knowledge and information about the Travelling community was seen as a problem. Providers are keen to do the right thing but not always armed with the right information. Streetly (1987) highlights the fact that misunderstandings often arise because health workers lack knowledge about cultural beliefs and outlook on life. Complaints about 'dirty gypsies' from people who have never seen the Travellers' way of life, or the inside of their trailers, compound these misunderstandings.

Service providers realised that there is a lack of knowledge among the public, including Travellers about palliative care and its role in the care for the dying patient. This frustrates palliative care staff:

I think there's a lack of understanding in some of the hospitals about what we are exactly about despite that they have been told over and over again and we are still being referred to as the cancer nurse, the stigma of that is just....its like the old days of the TB and its still there in a big way. I don't like actually being called a cancer nurse because I'm not actually a cancer nurse, that's not my

^{7 7} St. Luke's Hospital, Rathgar, Dublin; major radiotherapy treatment centre

job. You nearly feel like the death nurse coming in. That's all lack of education really, you know. (Homecare nurse)

Some service providers suggested that a lack of trust of service providers by Travellers might affect how they can carry out their work. Palliative care professionals may be seen as part of the settled establishment and perceived by travellers as not supportive and discriminatory because of this.

Service providers discussed ongoing prejudice towards the Travelling community. This extends to life in general and not just palliative care services. The possibility of prejudice against Travellers in primary health care and hospitals was raised. Another issue service providers thought may arise was the need to help Travellers to access other services and entitlements when a family member was seriously ill or dying. Palliative care professionals were concerned that travellers may not be able to access GP services or get equipment, such as pressure-relieving mattresses.

Service providers were aware from their experiences and from what they may have been told, that Travellers may react to bereavement with a more demonstrative, emotional response than the majority of settled people. Some wondered if this would present problems for staff, but was recognised as a part of normal grieving for many cultures.

Using medical terminology and unfamiliar concepts when talking to Travellers were also concerns. It was accepted that you would have to approach conversations around death and dying carefully. The importance of hope, and a very strong belief in prayers, cures and saints could make open discussion of dying difficult.

A number of service providers talked about security as a possible issue. In most cases they were considering security in relation to visiting sites or group housing schemes. In most cases they admitted that popular stereotypes of aggressive Travellers were behind these worries and that these concerns also existed working with settled people in certain areas of Dublin.

In the course of discussion the different way in which Travellers involve their children in the dying process was thought might cause difficulties for some service providers. When this topic was raised in the focus groups with Travellers they pointed out that they felt it was not appropriate for children to be around the death bed of someone they did not know, but if it was a family member they were very familiar with that that was seen as appropriate.

When a patient cannot read, certain difficulties can arise in relation to their care. Service providers talked about the need to be aware that some Travellers may not be able to read, which may affect Travellers use of medication. Working with people who cannot read presents a challenge that must be met with sensitivity and understanding by all involved in the care of the patient and their family.

Medication

Many raised the issue of drugs and medication in relation to treating and caring for Travellers. It emerged that morphine and the fear of addiction is a concern that is often expressed by patients and their families. Some were concerned that leaving drugs such as morphine in trailers would be a security risk for the patients. This is

also an issue for settled patients. When raised in the focus groups Traveller participants were in general happy for a nurse to come and administer pain relief such as morphine or for it to be left in the trailer; they did not anticipate any problems. Some service providers mentioned that there are a variety of ways in which medications and drugs can be administered that might overcome these concerns, which in any case are also relevant for settled patients.

The issue of compliance was raised a number of times by several service providers in the interviews and focus groups. Many felt that there was a nomadic aspect to Travellers' way of life that would prevent compliance with palliative care and treatment. Concerns included: early self discharge, mobility issues and compliance with taking medication. Being non-compliant around medication was seen as potentially frustrating for service providers. Others questioned how Travellers viewed conventional medicine and whether a lack of compliance was a result of not believing in the medications effectiveness. Some service providers felt that compliance may depend on age and improve with increased education. However, it was made clear that compliance was also an issue within the settled community. When discussing compliance it was clear that the understanding was that, ideas the medical establishment has about treatment, may not fit with the perceptions that Travellers have about such things. Never was it implied that Travellers are non-compliant in an intentionally disobedient way.

Most service providers felt that the stereotype of all Travellers drinking heavily was untrue and unfair and that although alcohol was a concern, especially when grieving or upset people were drinking, this was seen as equally likely with people from the settled community. In fact, most service providers were quick to mention that many of the issues they have either experienced or anticipate with Traveller patients and their families are also common to the settled population. They cautioned against pre-empting any situation with Travellers as a result of popular stereotypes rather than real experience.

Changes necessary

The service providers who took part in this study felt that a number of changes from within their service were necessary to deliver an appropriate service to the Travelling community.

It was suggested that, to encourage Travellers into the hospice service, there was a need for a partnership approach with Travellers and that palliative care services should engage more in education about the needs of ethnic minority groups such as Travellers. It was also suggested that staff embrace the notion of compromise and admit that they, no more than any one else, do not always know the most appropriate way to approach a situation, especially with people from a different ethnic group. Service providers may be willing to embrace other cultures but need guidance on how to do this:

You can get people who are very sensitive to the fact that we need to adapt to the Travellers' culture but we don't know what's the best way to do it. (Social worker)

It was noted that instead of expecting the Traveller to adapt to settled ways and to services designed for settled people, the health services should adapt their services to suit the needs of the Travelling community and not always assume existing services are appropriate to all ethnic groups. There is a need for service providers to treat Travellers as individuals, just as people from the settled community would be treated, and a need to suspend the popular stereotypical views that may influence how some people approach cases involving Travellers.

There needs to be a concerted effort on the part of service providers, it was suggested, to meet with Travellers to inform them of the services that are available and to hear what they in return want or need from the service. One way to establish a connection with Travellers might be to link with existing educational programmes to inform Travellers about the services. Service providers who took part in this study agreed that a lot of education was needed in order for Travellers to be aware of the services and to understand what was on offer. It was stressed that this had to be education that was appropriate for Travellers and their specific needs.

Liasing with other service providers, who work with Traveller communities, was also seen as important. This would provide vital information about the patients and their family. Given that many palliative care service providers have limited if any experience of caring for Travellers, such local knowledge would be invaluable.

Some service providers felt that reasonably simple solutions could often be found for what people considered to be big problems. With Travellers, the issue of large crowds visiting and staying in the hospitals and hospices was often cited as one of the most potentially difficult aspects of having Travellers as patients. One example of how this situation was handled was supplied by a participant, who rightly notes that forward thinking and planning may avoid this problem:

I can remember very clearly, well it wasn't an issue, well it was helped by the fact that the patient died during the day which is maybe a little bit easier than when you are trying to manage at night time with less staff... the patient was in a single room and we moved the patient when the patient actually died to a large room that was actually able to accommodate them, and we were able to just cut them off a little bit from the ward and just give people as much time as they needed. Then they went to our coffee shop and I would make no apology for that, that was the way it was and it worked out very well. We had planned what would happen around the time of death and how we would facilitate that.
(Specialist palliative care nurse)

Some suggested that an issue in relation to Travellers was lack of bereavement support. If a patient and their family have been using hospice services they are usually linked in with the bereavement service. If talking to a professional stranger / counsellor is not a favourable option for Travellers, then the existing support services can think about supporting those that Travellers talk to, frequently priests known to the travellers. Bereavement support volunteers from the Travelling community could visit bereaved Travellers at home to provide support. Some service providers talked about Travellers attending bereavement support offered by many of the hospitals and hospices. One service provider recalled asking a Traveller who had lost a family member if he wanted to attend the bereavement session:

'It's funny' he says 'that's not really part of who we are at all', whereas I would have thought the story telling fits in with it ...he just couldn't see himself coming up here, for Wednesday nights, sitting down listening to a nice lecture about grieving. So he was very intimidated about the idea of coming up and sitting in a room with other people. (Social worker)

The Traveller's response made this service provider re-assess the bereavement service they were running and realise that it was not being accessed by Travellers and possibly not geared towards their needs.

In Summary

This chapter summarises the views, opinions and ideas of the palliative care service providers who took part in this study. The level of experience of having cared for or treated Travellers was examined as well as the views of participants on service use, preferred place to die and some insights into the matter of cultural diversity. Participants views in relation to issues arising in delivering a service to the Travelling community were explored. Service providers were realistic about the issues such as: compliance, security, cultural difference, communication difficulties and illiteracy. Service providers thought some areas needed addressing. These included the need to reach out to the Travelling community, to forge links and open pathways of communication. The service providers were quick to state that the issues that they perceive as potential difficulties in delivering a service to the Travelling community are in the majority of cases issues that they have also encountered in caring for those in the settled community. The main issue of cultural difference is one they wish to embrace and accommodate, stating that the service is eminently flexible and that they are willing and eager to learn how they can adapt the service to meet the needs of Travellers. The message that comes through from the participants is that respect for difference and individuality is central to their approach and philosophy as palliative care service providers.

Palliative care services: access by ethnic minorities

This chapter considers the use of palliative care services by Travellers in the ERHA region and drawing on other research, explores issues that exist for ethnic minority groups accessing palliative care services. The views of the Travellers and service providers who took part in this study are then presented, providing possible reasons and solutions to matters that influence use of palliative care services.

Perception and prejudice

All service providers who took part in this study were curious as to why they were not meeting Travellers in their work:

Tell them we're asking 'Where are they'? (Homecare nurse)

It was only when you said it that I thought why haven't I seen more, where is the problem, is it with the system or is it elsewhere? (Palliative medicine consultant)

They were also clear that the palliative care services are eager and willing to care for all people no matter what their culture, religion, ethnicity etc. The report of the National Advisory Committee on Palliative Care highlighted the need to recognise and facilitate cultural difference:

Ethnic and cultural diversity is now a demographic reality within most western societies and cannot be ignored by specialist palliative care services. All cultures and religions have particular beliefs relating to dying, death and bereavement. The Irish Traveller community also has different ways of looking at death and bereavement. Palliative care professionals should recognise and facilitate cultural difference.

That report also notes that there are many common pitfalls in dealing with patients of different cultural backgrounds. These include making assumptions, stereotyping and prejudging what other populations want, based on previous experience. The report notes that education is the key to the provision of culturally appropriate care to patients and their families from all cultural backgrounds. They also note that getting to know local leaders in the community could be helpful when dealing with patients, as well as recruiting volunteers from the same cultural background. (Report of the NACPC 2001).

Research carried out in England on hospice and palliative care service use by black and ethnic minority communities identified factors that lead to the perceived low take-up of these services. These include:

- The lack of accurate data on the ethnicity of people using these services.
- Death from cancer occurs mainly in older people (aged 55 and over). The age profile of the ethnic minority populations with a smaller proportion of elderly people could account for low uptake.
- The majority of people receiving hospice and specialist palliative care are people with cancer, and cancer causes fewer deaths in these ethnic minority communities.
- There is little or no information available to ethnic minority patients and their carers about these services and they are also not being advised about them (Hill and Penso 1995)

The findings identified a need for hospices and palliative care services to provide culturally sensitive services in respect of language, religion, spiritual and dietary needs, and for particular attention to be given to providing appropriate and accessible information to these communities. They also note the need to put in place ethnic monitoring and a more consistent referral arrangement from GPs and hospitals (Hill and Penso 1995). Smaje and Field (1997) write about ethnicity and the use of palliative care services in Great Britain. Focusing on ethnic minorities, they discuss the widespread feeling in the British palliative care community that people from the minority ethnic populations are under-represented among the users of palliative care services.

McNamara *et al* (1997), writing about health care professional perceptions of palliative care in a multicultural society, found that education was key to the provision of culturally appropriate care to patients and their families. They noted a range of resources that palliative care professionals found helpful when delivering cross-cultural care. Particularly useful were health care professionals and volunteers from the same cultural background. In terms of education, lectures and interactive workshops with professionals and ethnic community representatives were recommended, also short courses on culturally appropriate palliative care as well as written and visual aids.

A study of nurses in the UK showed that there are difficulties in communication with patients from ethnic minority groups in general and a lack of knowledge about cultural differences. The study demonstrated a need to develop cultural knowledge in nurse education programmes and that nurses need help and support with communication difficulties (Murphy *et al* 1993).

Waddell *et al* (1997) note that there will always be variation in beliefs even among families or the same cultural grouping and palliative care professionals must be wary of culturally stereotyping individuals.

Service providers who took part in our study were clear that their philosophy of a holistic caring approach seeks to ensure that all people are treated equally yet with respect for difference. Questions constantly asked included whether Travellers felt comfortable talking openly with strangers about cancer, dying and death. Were they willing to hear about diagnosis and prognosis of their family members, will they accept help at home with caring for the dying or will they allow their loved ones to be cared for in a hospice? This chapter will try to shed some light on these questions, using the data collected in this study, and offer some possible reasons why currently Travellers rarely access palliative care services.

Need and access

Some service providers felt that the limited use of services may be due to the fact that Travellers are dying from illnesses other than cancer and therefore do not require the services. As Travellers do not live on average as long as settled people, they may not be living long enough to get cancer:

I would wonder if the health status of the Travelling community is not that great so a lot of people would die from other things, you know they don't live long enough. The reality is that cancer is still a disease of older people, I

mean we always hear about young people but cancer is a disease of older people and many Travellers I believe don't live to develop cancer. (Specialist palliative care nurse)

Current evidence tells us that Travellers are more likely to die from coronary heart disease and respiratory disease than cancer (Pavee Point: fact sheet: Health). Therefore, one issue in relation to use of palliative care services by Travellers centres around the services' focus on treating and caring for patients with cancer, HIV/AIDS and Motor Neurone Disease (MND).

Palliative care as a 'secondary' service relies on other health professionals for referrals. Service providers felt that it was unlikely that Travellers are not using the services because they have not been referred to them. The referral criteria are relatively objective and service providers did not believe prejudice would prevent referral. Once in the hospital system the procedure would be to refer patients to palliative care when that level of care was required:

M: From a referrer point of view it wouldn't make any difference if they were from a Travelling family or a settled family, it makes no difference. So the block isn't certainly at our end and nor is it at the hospice end where all the patients are being treated the same. So is it that they are just not being picked up or are they not being compliant are they not following their treatment plans or are they being lost to follow up or are they reluctant to come back for a review.

M1: I think they just drop out themselves.

M: Is that what's happening? I wonder, because they would be automatically referred to us if they had incurable disease but we are not getting them.

(Specialist palliative care nurse and palliative medicine consultant)

There is some evidence however, of passive prejudice whereby minorities are under referred (Karim *et al* 2000, McNamara *et al* 2001) because of referrers' beliefs about how patients from ethnic minorities are cared for by their family and because ethnic minority patients are more frequently not informed of their diagnosis.

Providers also suggested that Travellers may encounter difficulties in accessing health services prior to getting to hospital:

You know you have to have access to all the other steps along the way to actually make it to palliative care. So, you have to be involved in primary care and you also probably have to get into secondary care to have your diagnosis of cancer and to be treated and to go through that system...Palliative care wouldn't be the first point of contact. So unless members of the Travelling community have actually come into contact and are regular attenders in the other areas it's unlikely that we would come into contact with them. (Palliative medicine consultant)

Some service providers felt it was because Travellers were unaware of the existence of the services:

I would say they are totally uneducated about palliative care, they wouldn't know what it was because they wouldn't have had the chance to hear what it was. (Palliative medicine consultant)

However, others felt that Travellers were well informed about the services:

No in my experience the Travelling community are good at accessing services and they do know what's available and that's the Travelling community that I deal with and I wouldn't have thought there was any great problem, every one has GPs and every one knows where the service is. (Doctor, homecare team)

Another service provider in the same group agreed, that the services themselves were such that it would be unlikely for a Traveller not to be informed:

They are educated about what services are out there and now that there are oncology liaison (nurses) and a lot more information-based nurses in hospitals it is unlikely that somebody would be given a diagnosis and not made aware of what services are there. (Homecare nurse)

It was proposed that one reason why Travellers knew so little about the service was that the service does not promote itself sufficiently:

People in general do not have a good idea of what palliative care services are about. My own theory on it is that palliative care has deliberately not been good at telling people what we are all about so that we can limit the numbers who are coming to our service. (Social worker)

For a variety of reasons including fear of cancer and death, Travellers may be unwilling or unable to access services. Participants talked about how Travellers were afraid to go to certain hospitals due to the association with cancer. Fear of places associated with death in general was noted as possibly a barrier to Travellers accessing services. Travellers might be reluctant to go into a hospice or hospital to die as they may feel that they are giving up their own sense of freedom and would have to conform to the institution's way of doing things:

Maybe they feel that if they go into these orthodox, conservative places to die or to be treated that freedom is taken away from them... So maybe they just decide to go their own path and do their own thing. (Homecare nurse)

This last point was supported by what the Travellers themselves had to say about their own fear and mistrust of health services. In most cases Travellers talked about general health services and general hospitals of which they have experiences. Some felt that once left alone in the hospice a dying person suffers from loneliness, especially when most would be accustomed to having many people around them in every day life. Drawing on personal experiences of having family members cared for in homes, some Travellers noted how being around the family is central to caring for the elderly in their community. Some felt that hospital and hospice care actually speeds up the dying process for Travellers:

To me they die quicker... it's the fear and then when you leave them, you can only stay there so long. When you're at home you're with them 24 hours even if you're not in the one room they know you're there. When they're up there and you leave them you feel kinda guilty... it's probably that the place is too good... but then it's heartbreaking to go out and leave them there and to me they get sicker themselves. (Traveller)

One other service provider suggested that Travellers are still treated as a marginalised group in Ireland. The resulting lack of empowerment and discrimination are major barriers against service use and access. In many cases the Travellers who took part in

this study felt that they were not treated with respect by healthcare staff to the extent that they are put off returning.

Service providers saw the nomadic lifestyle of the Travellers as another possible reason for not using or accessing services, especially if contact with primary care givers such as GPs and public health nurses was limited and that using the services might be seen by Travellers as curtailing their freedom to move around:

S: Maybe they are aware that it is a domiciliary service and they might not see themselves as domiciled, you know what I mean.

M6: Do they see it as an invasion of their ability to roam around, if they are linked to a person do they have to remain linked to that person, would they see that as an obstacle...(Homecare nurse)

Cultural differences between the settled and Traveller communities in Ireland impact on every aspect of life. Many Travellers have a different view on what constitutes health or ill-health and what warrants a visit to the doctor or the hospital:

Just that I feel that Travellers don't look after themselves, maybe the younger ones do now, the older people wouldn't look after themselves as well as settled people would. They get a pain in the head or feel sick they won't go to the doctor, as settled people would and therefore they could be ill and they mightn't know till it's too late to help them, some Travellers wouldn't go into a hospital. (Traveller)

Service providers offered a variety of opinions as to why Travellers were not using the services. In some cases it was suggested that they might choose not to use the services as they prefer to care for their own:

I suspect that there would be huge community support. I don't know a lot about Traveller culture but I know that families are large and that family seems to be important, I mean they do live in communities so I suspect one might be surprised at the resources that are there and the resolve that is there to care for people in their own setting. Maybe that's why we don't see people because they do it the way they have always done it and perhaps there might be a greater tolerance and acceptance of suffering and hardship and maybe people just consider this to be part and parcel of what happens and they get on with it. (Palliative medicine consultant)

It was suggested that perhaps it is not an issue that Travellers are not using the services. It was presumed, though, that other health professionals were looking after them:

Have we any evidence that they are dying worse deaths from lack of palliative care? I mean maybe they have more involved GPs or whatever, I don't know. (Palliative medicine consultant)

The way forward

In palliative care, ways need to be found to tackle the apparently low utilisation of existing services among ethnic minority groups. Smaje and Field propose actions at a number of levels. First, people from all ethnic groups must know about the existence of services and how to access them. Although they recognise that this presents a

challenge they maintain that it can be achieved by developing expertise in multicultural health education among health agencies. Second, efforts must be made to tackle prejudice, racism and ethno-centrism in the provision of palliative care. Much of this can be achieved through staff training, high-level management action and appropriate staff audit procedures as well as continued attempts to develop procedures and environments to address the cultural and religious values of all users. Third, they stress the importance of all users having access to the full range of services available such as pain control, respite services for carers and bereavement support in appropriate settings (Smaje and Field 1997)

Traveller participants suggested a number of actions to address what they felt were the main areas of concern in relation to service use. First, they noted that being aware of how Travellers may behave in certain circumstances could only help the healthcare professionals carry out their work:

You see that's where the doctors and the nurses should learn the culture of Travellers coz when K was told what she had and that her breast would have to be removed, it was an awful shock to the family and especially to the men more than the women. The reason why I say that is that the women stood kinda calmer. Travellers comes out like ourselves here with a very broad kinda voice and I was there when the doctor was there. So I explained to the doctor don't be frightened or terrified coz they're hysterical at the moment but that's the way we have for talking. (Traveller)

They want healthcare professionals in hospitals to have more respect for Travellers and to be more understanding. When asked how could clinical staff learn to be more respectful towards Travellers, they suggested:

L: By talking to them.

M: By seeing them in a meeting.

H: Mightn't be the nurses fault sometimes when they have so many sick people there. (Travellers)

They said that clinical staff need to be aware that when a Traveller is very ill and or dying the whole family will want to be there and to be kept updated on the situation. In the case of Travellers, where large crowds gather due to the large size of families, it is seen as important to have a room where news can be broken in private and crowds can be away from the corridors where they may be hindering the staff movements. Service providers also suggested single rooms and a space for visitors as a necessary consideration for Traveller patients and their families. Some hospitals do take people aside in a room and provide support and comfort for the bereaved but this was seen as unusual:

I think Temple Street Hospital⁸ are very good... because they know what to do for you when anything like that happens... They put us into one room, there's a nurse in there and a social worker came in and looked after them and they didn't mind the kids the way they were running around and looked after the kids and gave them this and that and talked to them, talked to the parents and all. Some of the hospitals you won't get that. (Traveller)

⁸ The Children's Hospital, Temple Street, Dublin; an inner city children's hospital

It is also important that clinical staff realise that on occasion if Travellers are not asking questions or giving any responses it may be out of embarrassment at not understanding what is being said, or fear that if they do express an opinion that the security staff will be called:

L: You're ashamed to talk back to them because they think they know more than you do, and they do and there could be some big words that you don't know what they are saying to you if you don't want the security guards out, you're just better off not saying anything.

M2: That's what the Travellers say, 'don't say nothing'.

L: But do ya notice the way they get the security guards for to get the Traveller away out of the hospital.

M2: 'Please don't stand in that area, there's people coming in and out'

L: 'Come on now, move along'. (Travellers)

The service providers who took part in the study suggested a number of areas where changes were necessary. Service providers may feel that everyone should use their services and that everyone would benefit from the services when in fact it is important to realise that the services are not obligatory and that the service may not suit people in its current form and may have to be adapted:

We have to not be patronising and think that people have to use the service, and equally if there are parts of the service that would be useful and others not then I think we would be open to adapting the service. (Social worker)

It was proposed that one way of tackling the lack of information and awareness of the palliative care and hospice services would be for Travellers with experience to pass it on to other Traveller groups. Other Travellers may be more inclined to listen to and accept the experiences of someone from their own community:

I think what might be good would be to get someone who might have had experience of a hospice setting, a Traveller who has had a positive experience to meet with the groups themselves, because nobody can really understand where they are coming from other than those from within the community themselves, and maybe to hear from them that it's not a bad thing and that it can help, but you'd have to find someone who had had a positive experience as opposed to someone who didn't, but maybe that might help. (Specialist palliative care nurse)

It might be something too that starts off like the way the whole palliative care thing came into being anyway and maybe it would be word of mouth that you might end up going to one family and hopefully if it went well that they might say that that was good and they see it then that someone didn't die in pain and that it won't be as sinister as they think it was going to be and it might just evolve like that. (Homecare nurse)

It is also important that Travellers are made aware of services such as the palliative care outpatient clinic at St Luke's Hospital. To date it is not known whether any Traveller has used this, but this clinic could go some way to addressing the issues raised by Travellers and service providers. This service, where patients and their families can be assessed by a palliative medicine consultant, specialist palliative care nurse and other members of the multidisciplinary team; and have relevant

investigations carried out, may meet the needs of travellers. Hospital palliative care may be associated with more hope, than hospice care.

“You could offer them options and you would present it to them in a very positive way.

This is to help when you have got an illness like cancer and that it effects people in different ways and the options are that somebody could come to your own home if you want that or you could come to the hospital for an outpatient appointment and see the doctor and see the nurse and see everyone who you would need to see’, a one stop shop which they might find more acceptable. I suppose the patient might feel they have more control because they are coming because they want to, and they can leave when they want to and there’s nobody coming and invading their space. I would sell it to them as a means to get their physical symptoms sorted and to meet with a doctor who would be happy to talk through with them and their illness and the impact its having on them and any difficulties it is causing, and who is willing to help in any way that they can. (Palliative Care Consultant)

In summary

This chapter explored some of the issues, presented by both Travellers and services providers, as to why the palliative care services are not being used by Travellers or accessed to any great extent. Judging by what the Travellers and service providers had to say, Travellers use of palliative care services is influenced by many factors. For Travellers, fear of cancer and institutional care are central, fear of prejudice and mistreatment is also present. Many health services in general do not accommodate the needs of Travellers, such as providing clear explanations of medical matters and space to accommodate visitors. The practical barriers to accessing services include lack of information and awareness of the services. Service providers identified issues such as mobility and lack of awareness as central. Cultural differences exist between Travellers and settled people and suggestions were made to address some of the issues arising out of these differences. Travellers stressed the need for service providers to try to understand their needs and to take time to express themselves clearly so that Travellers could understand them. Straight forward steps were suggested to improve relations between the communities, such as a waiting area for visitors. It was argued that maybe it is not a serious issue that Travellers do not use the services, provided this is their choice and not because they cannot access the services for practical or cultural reasons.

Difference; how the other is viewed

This chapter looks at difference, and the differences that are thought to exist between Travellers and settled people as expressed by the participants in this study. The Travellers compared themselves and their customs and way of life to those of settled people, or 'country people' as Travellers call them and it was largely the Travellers who stressed the differences. They talked about how they as Travellers were treated differently to settled people by the healthcare professionals. They then talked about the different attitudes, reactions, behaviours and customs relating to dying and death. In many cases those talking went to great lengths to ensure that they were not being disrespectful in saying these things, just pointing them out because they were asked.

Different treatment

A re-occurring issue around Travellers and palliative care is the question of crowds. Much was said about the numbers of Travellers that gather when a family member was ill or dying and then at the funeral afterwards. Both Travellers and service providers saw this as a potential difficulty. It was clear that the phenomenon of large funeral crowds is not as common in the settled community:

With Travellers, the way it is, if someone in your family or a friend or a cousin gets sick and is dying well Travellers go in a big crowd and then there's too many people at the hospital then and the nurses can't cope. With settled people it does be different probably, three or four with someone dying when they're in a room like but with Travellers there could be three in the room with the person that was dying but there'd be crowds outside the door.

(Traveller)

Probably now in the hospitals where a Traveller is dying the man's family would be outside, they'd sleep in the vans outside the hospital, they wouldn't go home and there'd be relations outside, sleeping outside waiting for the news, they wouldn't go home. (Traveller)

It was noted that often Travellers are treated differently to settled people because they are from the Travelling community, as in this account of the scene around a removal:

I remember very dramatically the experience of the actual removal when... the body was being removed and outside as you probably know, there are very poor parking facilities here and there were several vehicles parked around and two young gardai ...extremely abusive verbally to members of the family who came to attend the removal. There were vans, they were Hiace vans, the gardai could clearly see that these were members of the Travelling community and they were verbally most abusive, demanding that they must move these vehicles, when in fact I think they would have dealt with other people who weren't Travellers in a very different way because equally around here there can be chaos at different times around removals. So I was quite shocked by that experience. (Social worker)

The Travellers and service providers who took part in this study all raised the issue of prejudicial clinical care as experienced by Travellers. This was also raised in relation to the barriers that may prevent Travellers from using palliative care services, but applies to health services in general:

I had a cousin that was killed in an accident out on the road and he was brought out there and he was a week in the hospital and I remember us all, everyone was going in to see him coz he knew he wasn't going to make it. I remember us going out and they wouldn't let us in to see him. So they never wanted any crowd in, they never wanted a crowd to be there and there was no welcome for the Travellers. (Traveller)

Stereotypical perceptions about Travellers can influence service providers, who may react differently to a Traveller, possibly based on expected behaviour rather than any real experience:

Sometimes the perception is that some of the Travellers are going to go off and be drinking. It's completely stereotypical but it does happen as well. Somebody might park just outside and the security guard will follow them up and they say 'lookit, I have no place else to go, I can't afford the car park, I don't have any money, what do you expect me to do'? Some people say okay we'll try and sort something out, but it doesn't fit and then what inevitably happens is the anger... no matter how much people say that 'we're trying our best' they do react quicker to that type of anger and suddenly I get a referral 'there's a Traveller who's drunk up here' and then it becomes a security issue. (Social worker)

The Travellers taking part in this study remarked on the differences between them and settled people. Often it would be noted how much better settled people were at certain things, being better educated and self-confident. It was suggested that settled people are more aware of their entitlements, more confident around healthcare personnel and less likely to get embarrassed in situations around medical care and hospitals:

L: It's a way of looking at it, a settled person would know more about their rights than a Travelling person would. We mightn't have as much education as to what they have.

M2: Like if I were in the hospital now and the doctor came over to me and said to me 'please leave the hospital', I'd leave the hospital, I wouldn't say well 'why' or 'why are you not asking her to leave and you're asking me to leave' I wouldn't say that, I'd just walk out of the hospital.

*L: It's embarrassment.
(Travellers)*

Leaving a family member in a hospice or home was discussed on many levels (See chapter 2). It was felt that settled people seem more comfortable with this than Travellers, who feel they are too close to their families to leave them in a hospice. Settled people, according to Travellers, are better at letting go:

M: I'm not being ignorant when I say this but I just find that settled people can let them go, like we wouldn't even considered me mother or father going in to it, if there was some of us to mind them, do they really want to be going there or to be putting us to anything like that.... and as K says her daddy'd be lost up there, that's the way we'd think of it and they could probably give them better care than we could ever give them but to us they'd be lost and to their ole brains god help them they'd be lost as well, that we are leaving them, you know the way....But I thinks that settled people has great

willpower that they can let that go and let them go in and it's great, you know what I mean but we wouldn't ... not to say there's anything wrong with that.
(Traveller)

Many Travellers talked about how their funerals are very different to those of settled people, notably ideas about what was to be done at the funeral in terms of behaviour, practices such as cremation, the after-funeral gathering and the tending of the grave after burial.

K: One of my cousins, like they had big food and sandwiches, it was like a proper do, like you know what I mean. Me daddy went to it but he was bewildered. It was just pure settled people's carry on, he was married to a settled woman. It was the same when our C died, she was married to a settled man, she got cremated and me daddy was bewildered...

M: That's one thing that Travellers won't do, even consider.

K: But she wanted to be cremated and we hadn't a clue where she was going to go or what way they were going to do it, where the coffin was goingthen they had a big wake, big loads of food and all.

M: Now every settled person does nearly do that, to hire out a pub and have a big kinda do, and that's just their way of kinda...we wouldn't have any of that.

K: Travellers would just drink they wouldn't bother with food.
(Travellers)

One woman recalled a funeral of a settled man in which there was food and drink and that it felt like a party, a celebration which even as a child felt wrong to her:

I remember... the ole man who lived beside us, we knew real well, died and I couldn't believe it there he was lying stone dead in the coffin and them all eating sandwiches and cakes and I was about eight years of age and I couldn't believe it...to me this was party stuff and yet this ole man was dead.
(Traveller)

As for funeral attendance, if Travellers know the person or even know someone who knew them they will attend the funeral. Most Travellers are either related or know each other well and therefore will attend most funerals that they hear of:

That's one thing about Travellers funerals as well, even you might not have known that person but you know someone belonging to them and there'll always be a big funeral and there might be another funeral with settleds and there wouldn't be quarter of the people, you know what I mean. (Traveller)

Once at the funeral, Travellers believe that they behave differently to settled people. In terms of matters such as self-presentation and expressing grief, it was suggested that Travellers will not be in the frame of mind to care about their appearance and will express grief profusely in an abandoned manner:

K: Like yer one's father's funeral. They were all calm and taking it easy.

M: Get up singing

K: Hair combed and makeup.

M: And our hair'd be standing and we'd have no makeup.

K: You wouldn't hear telling of grooming, the immediate family wouldn't hear telling of grooming yersel up like that, anyway and getting up singing in the church.

M: But that's their way of doing things, just different like. Some women passes out and everything.

K: Some would be roaring crying and some'd be just sitting there.

M: It's not that we are any more emotional than they are it's just that we do things different. Sure we'd love it if we could take it that calm, you'd love it if you could get groomed and put makeup on but you just can't do it. I suppose it depends who it is, women would be very cut up over children.

(Travellers)

Ideas around tending the grave after burial were seen as being very different. Travellers were puzzled and upset that settled people do not tend to or even visit the graves of their deceased in a more caring and organised manner:

K: I see some graves and they are there since the 80s and they haven't even got a headstone or a little heart or nothing and you feel sad knowing the ole grave is left like that and not even kept and no one visits, you know when you go to the blessings of the graves now every year and you see graves now and there not even a sinner beside them, it's like they never existed.

(Traveller)

Coping differently

Some Travellers felt that settled people and Travellers had different ways of coping with death and, indeed, with life. The Travellers in the focus group discussions talked about the huge impact that death has on them and the whole community, a shocking event that leaves no one untouched. They also noted how detached settled people appear to be around death, talking openly and freely about death and, in the eyes of some Travellers, having a better understanding of life and death:

Settled people don't seem to take things as seriously when it comes to ill health, not being ignorant like. With Travellers when you talk about cancer it's an awful thing to be talking about, but settled people don't find that a problem to talk about it. You often hear them talking about it. They are more free making about things, they understand life and death better I think. Especially when it comes to death, they understand how to let go. They've been learnt from a young age not to take it so badly. Whereas someone dies in a Traveller family, it's the end of the world, it knocks everyone back, from the youngest to oldest, it affects them all deeply like, they take it personal but settled people don't. You'd often hear 'sure she died, she had a happy death or she suffered a lot and all' and it doesn't seem to be that big an issue.

(Traveller)

As with death, it was felt that settled people appear to be better able to cope with life in general. Life events such as death and birth evoke a strong reaction in Travellers and their need is to be close to the situation. They noted how settled people can wait for a phone call about an impending birth whereas the Traveller is in the maternity hospital or camped outside eagerly awaiting news. Settled people are seen as being less impulsive and more organised than Travellers. Most Travellers felt that settled people are taught how to react in a calmer way and teach their children likewise whereas Travellers children are learning to panic from their parents:

B: It's the same at the birth of a child, they're all there. Like we slept in the van in the hospital grounds when my daughter went in to have her first baby...You'd never see settled people going to that extent. Travellers are all upside down and panicking, when is it going to happen, I can't wait, like you know. Whereas settled people just take it in their stride 'we'll just wait now and we'll have the phone call'.

H: They cope better.

B: The Traveller child is growing up looking at the mother and father panicking like that...but if they are taught from a young age that it's not a big deal and it's not a problem you're going to accept it that way too. So it has more to do with the way people are brought up, Traveller people have been brought up to be very close to each other and no body has ever tried to change it and I don't think anyone wants to change it, you know we are happy enough the way we are. What it comes down to mostly is loyalty.

(Travellers)

Similarities

In the course of the interviews and focus groups with service providers it became clear that settled people are often as uninformed as Travellers are about the palliative care services. Certainly a lack of awareness was not seen as a specific Traveller issue.

In some cases you have to work very hard to get the basics across to somebody. I wouldn't see that as just a reflection of the Travelling community. I think that us as a team, that any house that we walk into you just treat as an individual case and from beginning to end is an individual. (Homecare nurse)

On some occasions both Traveller participants and service providers were more likely to assume similarities than difference between the communities:

There'd be an awful lot of support from the family members to each other, that's very important. It's probably the same in the settled. The travelling community is very, you have to stick together. (Traveller)

H: Would settled people go to curing people?

M1: Would they have a patrin (pattern) every year?

P: Yeah they do.

H: Would they go to curing people?

P: Yeah they would.

H: Priests and nuns and all?

P: Yeah they do.

H: How would you know P?

P: They do yeah, sure every one gets cancer sure. (Travellers)

Although most talk in relation to difference focused on those that exist between the settled and Travelling communities, it was mentioned that difference naturally existed within the two communities also and good and bad people exist everywhere:

M: There's poor and well off in Travellers and in settled people. One Traveller might have this and another mightn't have it but then good luck if they have but they are then in the two places.

L: It's just like with settled people.

Mg: There's three categories of Travellers, there's the very very down and out who drink an awful lot and sell their horses and their ole caravan and any ole thing but still in all funny enough they are happy that ole way. Then you get the middle sized Traveller she has an ole decent sized caravan and a decent car on the road and okay fair play she worked for it right, him and her, so you get that Traveller. The other Traveller then who's high and mighty gets up on her bit in the air...

M2: Some people puts all Travellers down for one. Like if one Traveller has a fight its all Travellers. All Travellers are getting blamed for it but it's not.

M: There's good and bad in all of us settled and Travellers.

A: There's good and bad in every one, even the royalty.

*M: You get a nice ole settled neighbour, she's okay and the one on the other side is a Traveller and she's aiting the face off ya, and maybe you get a nice Traveller that's not aiting the face of ya and then the settled one ates ya. You can't win, you get good and bad on both sides, you might as well face it lads.
(Travellers)*

There can be differences too between Travellers that live in the country and those that live in cities:

K: Yeah there's a lot that has their own tradition and God knows what part of the country she was from and it depends on where you were born and reared up. There's a lot of Travellers that has different culture than we has, there's a lot of them has, probably them all has their own different ways.

L: Yeah you can't tar everyone with the same brush.

K: There's a lot of Travellers too, like in England there's different Travellers like when there's a wake they might cover all the tables with white sheets, even in a trailer, they do all the trailer up in white and they bring the coffin into it.

A: Different everywhere. (Travellers)

In Summary

Travellers and service providers alike raised some of the differences between Travellers and settled people. They noted how people from the two communities respond differently to illness, dying and death. In some cases there was a sense of confusion at reactions to death, such as the Travellers who couldn't understand why a grave was not tended or regularly visited. Travellers also noted how openly settled people discussed serious illness such as cancer and death. In most cases the Traveller participants respectfully noted the differences between the communities. Perhaps, being the minority ethnic group, difference is a challenging part of everyday life and thus to the fore when discussing how people behave in certain situations. Being aware of how Travellers note the differences between the communities offers valuable insights into how they manage their lives as a minority within the dominant population. It also provides an important opportunity for the settled population to hear how our behaviour and customs are viewed from the outside and to alert us to the fact that what we view as normal may in fact, on occasion, appear as abnormal to Travellers as their customs and behaviours can seem to us.

Discussion and Recommendations

All cultures have particular beliefs relating to dying, death and bereavement. As society becomes increasingly multicultural, so cultural issues become an important feature in health care, particularly in end-of-life care where questions of an existential nature are of great importance (Ekblad *et al* 2000). However, cultural issues have not been studied sufficiently in health, especially in palliative care. This project aimed to explore the relationships between Travellers and specialist palliative care services in the Eastern Regional Health Authority and the attitudes of Travellers and specialist palliative care providers.

There are no universal categories for understanding death; how people think about death is everywhere culturally embedded. One reaction to finding that one's own categories do not fit the realities of others might be to consider their ways to be uneducated, misinformed, superstitious, less developed, or in some way faulty. Such ethnocentrism is unhelpful. The more useful course is to become adept at learning, respecting and dealing with another person's reality, no matter how it differs from one's own (Rosenblatt 1997).

Fried (2000) notes that despite the multicultural nature of Australian society, healthcare services tend to reflect majority cultural values, which disadvantage people from minority groups including Aborigines. Indigenous Australians suffer additional communication problems, cultural misunderstandings, socio-economic disadvantage and racial discrimination, which further alienates them from such services.

The alienation and discrimination experienced by Travellers is one of the most important factors influencing the health service: 'The central problem for the Traveller population in this country is the hostility of the settled population' (Morris *et al* 1999). The concept of helping another is also culture bound, so when an outsider offers 'help' but makes no effort to understand what the person wants as 'help', may in fact not be much help at all.

Changing cultures

One important issue in the context of this report is the fluid nature of culture. Culture is not static but ever changing and adapting to changes in society. For Travellers the notion of a pure Traveller culture is as sensible as a pure Irish culture. All cultures are influenced by other societies around them. Acculturation occurs constantly without us being aware of it. Nyatanga (2001) stresses that we cannot afford to hold stereotypical views of cultures in their purest sense, but should acknowledge that they can be modified when exposed to other cultures. Nyatanga talks of acculturation in relation to ethnic minority groups in the UK, but the relevance to Travellers in Ireland is clear. The Travellers in Ireland have been exposed to settled ways and are slowly adopting some of them into their own culture. Therefore Traveller culture now incorporates many aspects of traditional Irish culture. Also each generation of Travellers will show different signs of familiarity and acceptance of settled ways. Younger Travellers may be more likely to attend school, for instance, as its value is increasingly recognised. Other popular cultural icons such as television and video games, mobile phones, etc., are all now apparent in Traveller lives.

Writing about Saudi Arabian society, Bonifant (2000) cites Mobeireek *et al* (1996) talking about the notion of individualist versus collectivist societies. In the *individualist societies* of European tradition, personal autonomy is the paramount ethic. There is a strong emphasis on personal achievement and the efficient performance of tasks; individual achievement and prowess is celebrated and there is a sense that anyone can do anything. In contrast, in *collectivist societies*, the group needs predominate, with the extended family and loyalty to the group being of prime importance. Individuals find identity through belonging and through relationships. Personal tasks are unimportant and the job can wait until personal obligations are taken care of.

Ekblad *et al* (2000) explored the issues around cross-cultural care with Swedish nurses in hospice settings. Many of the culture clashes discussed during the interviews touched upon differences between individual and group/family orientated thinking. In individual-orientated society, concepts such as individual rights, integrity and self-determination are important. In a group-orientated society, on the other hand, the individual is affirmed via his or her family and relatives; the individual is dependent on others in the group and also has obligations to group members. During Ekblad *et al's* study this emerged when patients' relatives were discussed: sometimes there might be many visitors, which staff could experience as problematic; the staff preferred to have contact with one or two relatives instead of them all. Thus the Swedish study raises many issues similar to those raised by the service providers in this study around communication and relating to those from ethnic minority groups.

Looking at Traveller society in Ireland it is possible to say that they have a collectivist society. Evidence from this study points towards the importance of the extended family, as well as the involvement of the family in decision-making and all aspects of care for the ill, the need for the extended family to be close to the dying relative and remain until after death has occurred. The suspension of work, school and courses for the duration of the illness, death and the funeral, highlights the dominance of family in this culture. Family are involved in every major event and every event is seen as a family event. The close family relationships and loyalty extend beyond death and are expressed in the visiting and tending of the graves. In contrast the settled community is closer to an individualist society. The point is that both groups have as their foundations different ways of thinking. And until both ways can be appreciated, communication and service provision, from one perspective to the other, will encounter difficulties.

Recommendations

A number of central issues emerged in this study, notably Travellers' lack of information about services and service providers' lack of information about Traveller culture, and cultural differences arising from different behaviours and ideas around illness, dying and death. The following recommendations may offer direction for both Travellers and palliative care service providers alike in addressing these challenges.

- **Awareness about services:** raising awareness about services within the Travelling community is central to addressing the question of service use. However, appropriate ways of informing Travellers must be used. Information in the Travelling community is largely passed on orally and received mainly

from television. Professionals have an important role in dispelling myths and taking time to explain medical matters clearly to a population with limited access to written information (Van Cleemput 2000).

- **Accommodating rituals, practices and beliefs:** cultural approaches to dealing with death are embedded in larger and well-articulated aspects of culture and society. Beliefs and practices concerning death should not be thought of as matters of taste but as vitally connected with much of a person's life. To understand a community's ways of dealing with death fully may require extensive knowledge of their culture, history, economics, politics, social class system, residence patterns and much more. However, even some basic training and awareness raising can result in an appreciation and greater understanding of cultural difference. Recent research focusing on health service provision for Travellers in the Northern Area Health Board (within the ERHA) noted that those who attended information days on Traveller culture presented by Travellers, gained a greater understanding of the barriers and difficulties that arise for Travellers in gaining access to health services. This also enabled the health service providers to accommodate some of these differences and provide a more appropriate service (Van Doorslaer *et al* 2002).

It is important not to stereotype. One can know things about the other's culture, know that certain beliefs and practices are common, but one should not assume that all people who come from that culture are alike. One's knowledge can be an asset. But one must not assume that everyone from that culture holds those beliefs (Rosenblatt 1997). Not engaging in rituals or having them shortened or undermined can leave people at sea about how the death occurred, who or what the deceased is, how to relate to others, how to think of self and much more (Rosenblatt 1997).

It may be difficult to understand and accept a grief heavily laden with joking and laughter, rage, wailing and lamenting or mute unresponsiveness. However, for the bereaved, the expression of emotions is sincere and heartfelt, fits what that person understands about death and grief, and is likely to be for that person the most desirable way to grieve. If one does not know the cultural background of a person who is making the effort to control emotions in ways that seem foreign by the standards of one's own culture, one may assume that one is seeing the expression of an individual personality or even a psychological problem. It is best not to separate individual from culture (Rosenblatt 1997). Hence the importance of being familiar with a range of the possible grief reactions from the various cultural groups that professionals in hospitals and hospices may come into contact with.

To inform palliative care providers about Traveller customs and beliefs a **checklist approach** may be of assistance. Caution must be exercised, however. Smaje and Field (1997) discuss the checklist approach where service providers may consult a list that describes cultural differences and highlights areas that may require special attention for people from different cultural backgrounds. This approach can have drawbacks as it presumes that culture is

static and unchanging; it can also fuel the construction of ethnic stereotypes by characterising particular groups in terms of cultural exotica. However it can be useful as a guideline for staff, and provide some basic knowledge. Smaje and Field note that this can have implications in terms of quality of care and can indicate a level of thoughtfulness and respect which in turn improves the quality of the encounter with patients: if basic information about religions and cultures is used as a resource in the interaction between users and professionals, rather than a prescription about what people belonging to the religion or culture are 'like', it may be of considerable benefit.

- **Collaborative approach:** service providers and Travellers must work together as a team. Imposing views and ideals will not encourage Travellers to feel part of the service. Smaje and Field (1997) note that the model for service delivery which is likely to meet with most success is a collaborative one in which palliative care professionals work with users, informal carers and local community groups to integrate services with community structures.
- **Accommodating cultural differences:** McDonagh and McCormack (2002) write about the Traveller experience of death, based on their experiences of working with the Travelling community in the Dublin area. They suggest a number of practical ways for palliative care staff to deal with situations that may arise with Travellers around illness, dying and death. Both Travellers and service providers in this study talked about the issue of large crowds visiting the sick and dying. Coping with these crowds can become a central focus for staff. McDonagh and McCormack suggest that staff identify an immediate family member and explain their difficulties, or else call on the priest or chaplain present, instead of immediately calling security, which can distress the family. It is also important for the family to be able to see the body of the deceased as soon as possible, as waiting can cause additional distress. It may also be that healthcare professionals may receive the brunt of the raw emotional response to the bereavement, something staff should be prepared for.
- **Education and training:** we need to educate palliative care staff in ways of approaching different ethnic minority groups to ensure appropriate care. This would also empower the care givers to feel confident to take on patients from any cultural or religious background. McNamara *et al* in their study of 191 Australian palliative care professionals highlight the importance of culturally appropriate education designed to improve professional competence and improve the quality of palliative care to patients and clients from all cultural backgrounds. They note the complex question of discussing the diagnosis and prognosis of cancer with patients and their families from different cultures, one that may create anxiety and a feeling of inadequacy amongst palliative care professionals. Nyatanga (2002) argues that it is important to ensure that education, both formal and informal, takes place in order to raise awareness of cultural differences in health, illness and dying. Nyatanga stresses that if education is to be successful, two main things are needed. First, funding to educate teachers, tutors and lecturers about how to teach culturally sensitive palliative care; if more professionals learn about multiculturalism they can appreciate diversity and incorporate that knowledge into their practise of palliative care. Second, authors of books on palliative care should include a

chapter on cultural issues and such a theme should also run through study days, seminars and conferences. Cultural issues should be seen as central to and not an optional extra in palliative care education.

- **Understanding one's own culture:** no clinical relationship exists in a vacuum. Fried (2000), writing about Aborigines, notes that no clinical relationship between a patient and a practitioner exists in isolation from the cultural, historic and socioeconomic contexts that shape their different lives. What is essential to the working relationship between those from different ethnic backgrounds is an open and non-judgemental attitude. Critically examining one's own beliefs and taking the trouble to understand one's patients' lives will assist in resolving many of the ethical dilemmas that arise from cross-cultural work and provide the basis for a humane service. One of the main findings of Ekbal *et al* was that to better understand other cultures it was important to raise awareness about the staff's own culture and to pay attention to culture especially in the context of the individual. According to Wright *et al* (1997) the first step toward developing cultural sensitivity is to increase awareness of each staff member's own culture. Cultural awareness also helps to avoid stereotyping about culture and behaviour.
- **Employing multicultural staff:** Wright *et al* (1997) propose that palliative care staff should encourage the administration to employ multicultural staff and thus respect the cultural differences among staff. This supports O'Neil's (1994) belief that the appointment of palliative care staff from minority ethnic backgrounds could be 'the single most effective way of helping ethnic minority patients and their families cope with the challenge of advanced cancer'. Although participants in this study did not suggest the employment of Travellers as palliative care staff, it was mentioned that local Traveller representatives who had experience of the services could present their experiences to other groups and spread the word about the service. What could develop, would be a role for a Traveller as a liaison officer between their own community and the palliative care services. This is recommended by several studies that address the issues of lack of use of the services and communication between palliative care staff and those from ethnic minorities. Randhawa *et al* (2003) in looking at ways to improve communication for South Asian patients in receipt of palliative care, recommended appointing a 'palliative care ethnic minorities liaison officer' to promote services in the community, encourage communication between service providers and offer staff support and experience. Jack *et al* (2001) write about the role of the Macmillan Ethnic Minorities Liaison Officer in Bradford, UK. This position is now well established and involves a combination of advocacy, advice, outreach and liaison work with a focus on supporting staff and service users with information on religious and cultural matters, gender specific issues, benefits advice and bereavement support.
- **Travellers being proactive:** once informed of the services, should Travellers chose to avail of them, then they need to formulate ways of obtaining information and passing it on to their community. Nyatanga (2002) maintains that the successful provision of culturally sensitive palliative care in the future will depend on minority ethnic groups taking an active part in seeking more

information about the nature of services available in their regions. However, it should be a two-way process. Nyatanga also stresses that it is important for both palliative care providers and minority ethnic groups to meet halfway to foster reciprocation. To create patient-centred and culturally sensitive palliative care, both the patients and the professionals have a role to play. In the Irish context, both Travellers and palliative care providers must want to address the issues raised in this study that relate to lack of service use by Travellers.

In Summary

It is clear from this study that few Travellers use palliative care and hospice services. The reasons for this, according to the Travellers and the service providers who took part in the study, are three fold. First, most felt that it is the family's responsibility and desire to care for the sick and dying at home. Within Traveller society, the extended family still exists to the extent that most families live close together allowing for a wide level of support for the carers of the sick.

Second, a lack of knowledge or experience in general about the services fosters well-established fears of the hospice, the 'death house' and in some cases general hospitals. Many fear the *idea* of these places, let alone having to go there or send a family member to die there. Issues around referral to these services also arose, with service providers being dependent on primary care providers and acute hospitals for referral to these secondary services.

Third, these services, especially the hospice, appear to be the domain of the settled person. Travellers who took part in this study talked about how 'their ways' do not always fit with these places. Service providers alluded to the fact that they may not 'fit in' with other patients. The cultural difference presents many barriers to service use. Yet the majority of those taking part in this study, both Travellers and service providers, were certain that with a bit of accommodation and flexibility both ways it would be possible to provide a service that Travellers would use, if they so chose.

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Appendices

Appendix 1: Focus Group Discussin Topic Guidline

This is a discussion about the care provided for Travellers who are seriously ill, some of whom may die from their illness. We are interested to know what is important for you and your families in such situations.

Cancer:

Experiences of cancer - family, others

If you had cancer would you want to know the diagnosis?

Would you want your family to know?

Treatment:

What sort of treatments are there?

Who should decide about treatment?

Death:

Is it right to talk about dying?

What about dying at home, in the hospital?

If a person has incurable cancer and will soon die?

Is it better that they die at home, in hospital, in hospice, other place?

Are there places which are particularly unsuitable, why?

Hospice:

What have you heard about hospices? (probe)

What about palliative care? (probe)

Symptom management

Have you heard of morphine?

Have you or anyone you know ever been treated with it?

Have you any concerns about using it?

Addiction / death

Care:

If a person is seriously ill, maybe dying, who should look after them?

What about pain and suffering? Religious or spiritual needs?

Who would you like to be involved?

Appendix 2 – Questionnaire for specialist palliative care service providers

Your Health Board Area is (please tick[√]): Northern Area Health Board

South Western Area Health Board East Coast Area Health Board

1 Do you routinely record ethnic origin? Yes No

2 Do you routinely record membership of the Travelling community?
Yes No

3 How many Travellers have you cared for in the last 12 months? _____

4 How many Travellers have you cared for in the last five years? _____

5 Is there staff training or education about Travellers available to you in your place of work?

Yes No

6 Have you received training or education about Travellers?

Yes No

If yes, please explain _____

- 7 In previous Traveller health surveys the following barriers to service provision re: Travellers were identified. Whether or not you have cared for Travellers in the past, please rate the extent to which you feel each of the following may or may not present a problem for you in delivering care. (Please tick the relevant box)

	1	2	3
	Not a problem	A Serious problem	Don't Know
Low levels of literacy among Travellers			
Your lack of awareness of different beliefs and culture held by Travellers			
Prejudice against Travellers from the public and service providers			
Poor appointment keeping by Travellers			
Travellers moving from place to place affecting continuity of care			
Large Traveller families involved, leading to overcrowding.			
Low attendance for follow-up care by Travellers			
Difficulty in discharging Traveller patients from hospital due to poor accommodation and limited hygiene facilities.			
Early self discharge by Travellers from hospital.			
Lack of compliance by Travellers			

- 8 If you have had experiences with Travellers which you think are relevant to the provision of specialist palliative care services please describe these below (or on a separate page).

If you have any further comments or questions relating to this study please contact Onja Van Doorslaer Tel: 087 298 1383 or Email: onja@eircom.net

Many thanks for completing this questionnaire. Your contribution to this study is appreciated. Please return the completed questionnaire to the collection box at reception. Your responses are confidential.



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