



BORD SLÁINTE
AN MHEÁN-IARTHAIR



Specialist Palliative Care Services Needs Assessment
Mid-Western Health Board
Cúram Maolaitheach

February 2004

MID-WESTERN HEALTH BOARD

**SPECIALIST PALLIATIVE CARE SERVICES
NEEDS ASSESSMENT**

CÚRAM MAOLAITHEACH

Specialist Palliative Care Needs Assessment for the MWHB area

Table of Contents

Foreword	
Acknowledgements	
Chapter One	Page 1
Introduction	
Chapter Two	Page 3
Aims and Objectives	
Chapter Three	Page 5
Methodology	
Chapter Four	Page 9
Morbidity and Mortality	
Chapter Five	Page 17
Palliative Care Service Provision and Utilisation in the MWHB area	
Chapter Six	Page 31
Qualitative Research Results	
Chapter Seven	Page 49
Quantitative Research Results	
Chapter Eight	Page 73
Discussion	
Chapter Nine	Page 75
Conclusions and Recommendations	
Appendices	Page 81

FOREWORD

The Palliative Care Needs Assessment Exercise arose from a recommendation of the Report by the National Advisory Committee on Palliative Care. This long awaited Report is most welcome and indeed will play a huge part in shaping the future delivery of Palliative Care Services in Ireland for the future years ahead.

The undertaking of this exercise was a collaborative approach between Voluntary and Statutory Agencies. It is this partnership to date that has pioneered the development and operating of the Specialist Palliative Care Services in the Mid West.

The professionalism and energy of those responsible for consultation, research and compiling the Report must be commended. This Report would not have been possible without their commitment, hard work and dedication.

The Mid Western Health Board in conjunction with Milford Care Centre is deeply committed to implementing the recommendations of the Needs Assessment Report and in particular on the basis of additional resources becoming available. Our aim in the Mid West is the ultimate service delivery goal for all patients who require Palliative Care throughout the region in that it is patient-centred, high quality, responsive, equitable and accessible.

We wish to thank the Minister for Health and the Department of Health and Children for their support and commitment to date.

Acknowledgements

This study would not have been possible without the cooperation of palliative care patients and their relatives who gave so generously of their time.

Thanks are also due to study participants who completed questionnaires, provided submissions and took part in focus group sessions alike. The direction and support of the Mid-Western Health Board Palliative Care Needs Assessment Steering Committee is acknowledged and, finally, thanks are due to Ms Geraldine Hussey and Ms Kathleen Hackett who provided administrative support. (Appendix One) This study was carried out at all times in a thoroughly professional and timely manner. A special word of gratitude is due to the Researcher, Dr. Orlagh Healy, Specialist Registrar in Public Health and the Research Assistant, Ms. Carmel Sheehy, Clinical Nurse Specialist.

Acknowledgement is also due to the Department of Health and Children, the various Health Ministers and senior Health Board Officials who over the years have been very supportive to the development of Palliative Care Services in the Mid-Western Health Board region; by setting up the Regional Hospice Steering Committee in 1991, followed by a Report on the Palliative Care Services in the Mid-Western Health Board Region – A Multi-Disciplinary Team approach (Riper, June 1995). A joint development plan was established in May 1996 between the MWHB and Milford Care Centre ensuring the further development of the palliative care services bringing them to where they are at today in achieving the optimum range of palliative care services for patients and their families in the MWHB region.

Specialist Palliative Care Needs Assessment For the MWHB area

Chapter One

INTRODUCTION

Palliative Care

Palliative care is the active total care of patients and their families when the patient's disease is no longer responsive to curative treatment (WHO).

Specialist palliative care services are those services with palliative care as their core activity. This level of specialised service provided by an inter-disciplinary team usually under the direction of a consultant physician in palliative medicine is referred to as "Level three – Specialist Palliative Care".

At an intermediate level certain patients and their families benefit from the care and expertise of health care professionals such as GPs Public Health Nurses (PHNs), General Nurses etc. who though not engaged in full time palliative care, have some additional training and experience in palliative care. This level of care is referred to as "Level Two – General Palliative Care".

Finally "Level One – The Palliative Care Approach" deems that all health care professionals should appropriately apply palliative care principles.

Study Background

Having been established in 1999 by the Minister for Health and Children, to examine the provision of palliative care and its future in Ireland; "The National Advisory Committee on Palliative Care" published its Report in October 2001. As a result of recommendations made in that Report the MWHB has undertaken this needs assessment for palliative care services in the Mid-West. Mindful that such services should be provided by a "highly trained and inter-professional team and delivered at a time and in a place that will be determined by the specific needs and personal preferences of each individual patient," this needs assessment has endeavoured to determine the epidemiology of illnesses likely to require a palliative care input, both malignant and non-malignant, and to seek the views of all key stakeholders involved in service provision and utilisation.

In March 2002 an inter-board management meeting hosted by the SEHB, and attended by representatives from the Department of Health and Children, (DOH&C), Eastern Regional Health Authority (ERHA) and the health boards, was convened. Following on this meeting, in order to standardise an approach to the needs assessment and to facilitate comparison between areas, all those performing the needs assessment, primarily of Public Health Physicians, agreed to coordinate their activities.

Core areas where inter-board agreement was sought included:

- Study methodology
- Questionnaire formulation
- Epidemiological data required for the study
- Sources of Epidemiological information

Because of the variation in the nature of services provided throughout the country, it is acknowledged that methodology will vary slightly between boards. Each board, however, has utilised data triangulation to increase the validity of study findings. Methodological triangulation involves the use of both qualitative and quantitative research methods. Space triangulation, the gathering of data from a variety of sources: i.e. patients of in-hospice, day care, home care and acute general hospital services, family members and community/ specialist service providers. Person triangulation is also used which involves interviewing both individuals and groups.

Chapter Two

Aims and Objectives

Aim

The aim of this study was to carry out a health needs assessment in specialist palliative care services in the Mid-Western Health Board area and to thereby determine the potential for improvement in those services for the region.

Objectives

The objectives of this study were:

- To describe the epidemiology of cancer and other diseases which may have a palliative care component using morbidity data, mortality data and population projections.
- To describe the current service provision and service utilisation.
- To determine the views and estimate the satisfaction of both service users and providers with the present services and to determine their views on how the services should best be developed, using qualitative and quantitative techniques.
- To make recommendations on the future development of Palliative Care services in the MWHB area.

Chapter Three Methodology

Demography and Population Projections

Population statistics were based on the 1996 census while population projections were based on CSO data with M1 F2 assumptions. M1 F2 are predictions of migration and fertility rates for Ireland under the present socio-economic climate.

Epidemiology of Malignant and Non-malignant Disease in the Mid-Western Health Board Area

The National Cancer Registry of Ireland (NCRI) kindly provided epidemiological data on cancer morbidity and mortality, specifically:

- 1) Cancer projections for the MWHB at board and county level.
- 2) Average incidence of common cancers over the five years 1994 to 1998
 - By county
 - By age groups (i.e under 18, 19 to 64 and over 65 years.)
- 3) Deaths as for incidence data
 - By county
 - By age groups (i.e under 18, 19 to 64 and over 65 years0
 - Place of death
- 4) The incidence of people with late stage cancers, with a potential palliative care need, based on 1998 data.

Palliative care services to date have focused on patients with cancer. The inclusion of non-malignant diseases with a palliative component poses difficulty, as almost all illnesses in their end stages would benefit from palliation though that is not to say all require the services of a specialist palliative care team. Secondly, many debilitating and chronic illnesses run a relapsing and remitting course; this creates difficulty in determining when the primary aim of treatment is no longer cure, if not sometimes impossible. Finally, estimation of the incidence of many diseases is difficult given the dearth of morbidity information.

It was decided therefore, at inter-board level, to calculate the prevalence of symptoms using estimates arrived at by Higginson et al in the UK, as the National Advisory Committee did. These estimates were applied to the population of the MWHB area to arrive at the number of patients suffering from non-malignant conditions who might benefit from a palliative care input.

Baseline Data Collection

Site Visits

All Specialist Palliative Care services and service providers in the MWHB were identified and each site visited by the needs assessment team.

The aim of these visits was

- To identify all Specialist Palliative Care services and service providers in the MWHB.

The objectives were

- Inform stakeholders of the needs assessment and enlist their support
- Inspect all Specialist Palliative Care sites
- Gather comparative data/activity levels
- Allow stakeholder input into questionnaire development and study methodology.

Description and Utilisation of Services

The specialist palliative care service provided in the Mid-Western Health Board region was described along with indicators of its utilisation such as bed occupancy, average length of stay, throughput, turnover intervals, admission rates, discharge rates, and death to admission rates and discharge to admission rates. Meeting with the service providers at the time of each site visit facilitated the collection of this information.

Stakeholders Perspective: Qualitative Research Component

This element of the study involved both one to one interviews with patients and their families and focus group sessions with specialist service providers. (Appendix Five) Interviews and focus group sessions were audiotaped and transcribed verbatim. Analysis was then performed using a constant comparative method to identify recurring patterns and themes.

Palliative care for children is not dealt with separately in this report, though they have been included in the epidemiological data. A national tender for a separate needs assessment in this area is being undertaken because of the small numbers per region and the requirement for an alternative methodological approach to assessing need in this unique subgroup of palliative care patients.

Patient Interviews

The advice of the Consultant in Palliative Medicine, Home Care Team and Day Care Sister were sought on the suitability of patients for inclusion in the survey as it is estimated that up to one third of such patients would not be fit to answer questions owing to imminent death or advanced illness.

All patients in receipt of specialist palliative care services who were resident in the Mid Western Health Board region at the time of the study were suitable for inclusion.

Patients who were deemed unsuitable by virtue of degree of illness or uncertainty of short-term prognosis were excluded from this study. The patient's consultant or home care nurse made this decision.

Within these constraints a total of five patients were interviewed. The final selection was broadly representative of the geographical spread and the range of the palliative care services currently on offer in the Mid-West, a patient having been selected from the inpatient unit, an acute hospital, day care, homecare and support bed unit and patients having been resident in both rural and urban settings.

Interviews were performed by a researcher who also has a background in palliative care with the fully informed consent of patients. Consent was recorded on audiotape, as was each interview. A list of topics to be covered in each interview was prepared by the author following a literature review which identified the main areas to be covered. The interviews took place in venues that were convenient for the participants either at home, in the hospice or in an acute hospital.

Interviews with relatives

Five relatives were interviewed. As in the selection of patients, relatives were chosen to reflect the variation in the range of services on offer and the geography of the board area. (Appendix 4.2)

Focus Group Sessions

A decision was taken not to hold focus group sessions for patients and relatives in view of the sensitivity and the vulnerability of these individuals brought together as a group. Three focus group discussions were arranged for service providers. These included senior representatives from all disciplines including nursing, medical and paramedical disciplines as well as representatives from the voluntary sector and the community involved in specialist service provision. Sessions were held in a Milford Care Centre meeting room.

The list of topics was compiled following consultation with service providers and a literature review that helped to identify possible key topics for these groups. (Appendix 4.1) An independent researcher experienced in this aspect of qualitative research acted as facilitator for two of the three sessions while the researcher who performed the patient interviews and the author acted as co-moderators for those sessions and facilitators for the third. The discussions were taped, transcribed and analysed.

Stakeholders Perspective: Quantitative Research Component

Questionnaires were designed using a template, which was developed for earlier palliative needs assessment in Ireland. The inter-board working group agreed the questionnaires at national level and then following on the interviews and focus group sessions this questionnaire template was modified to suit the local environment. Questionnaires (Appendix Three) were circulated by post for self-administration to:

- General Practitioners
- Specialist Service Providers
- Hospital Consultants (excluding Pathologists, Consultants in Emergency medicine)
- Directors of Nursing in Community hospitals
- Acute Hospital Nurse Specialists (who care for patients with potential palliative care needs)
- Public Health Nurses

Submissions

All interested parties were invited to make submissions as part of the needs assessment process. Advertisements were placed in the local press to this effect (Appendix Eight) with one response received (Appendix 6.5).

Data Analysis

Quantitative data were coded, inputted and analysed using the statistical package for social scientists Version 11.0. Qualitative data was analysed using a constant comparative method. Important analysis dimensions emerged from patterns found in the data using the techniques of content analysis. This involved the process of identifying, coding, and categorising the data to facilitate the search for patterns and themes and to demonstrate support for those themes. Data sources were analysed separately so that the data from in-depth interviews and focus group sessions with service providers were identifiable. This enabled cross-source as well as intra-source homogeneity or heterogeneity of responses to be analysed.

Chapter Four

Morbidity and Mortality

Morbidity and Mortality of malignant disease in the MWHB area

Cancer is a major cause of morbidity and mortality in the MWHB area. According to the National Cancer Registry of Ireland, cancer accounted for a total of 3,203 deaths in the MWHB area in the five years between 1994 and 1998. Sixty-eight percent (n=2,196) of these deaths were of persons aged over 65.

The commonest cancer in both males and females is skin cancer. Non-melanoma skin cancers are successfully treated and generally are not users of palliative care services. Non-melanoma skin cancers have therefore been excluded from this analysis. The commonest cancers occurring in the five-year period between 1994 and 1998 in the MWHB area are shown below in Tables 4.1- 4.4. These common cancers, bowel, breast lung and prostate are also among the most frequently seen by the palliative care services.

Table 4.1: Cancer incidence in the MWHB area county 1994-1998

Source: NCRI

CANCER	LIMERICK	CLARE	N. TIPP
All Mlgnt Cancers	2505	1312	1016
Colo-Rectal	349	178	115
Colon	211	102	72
Rectal, R'sigmoid Jn & Anal	138	76	43
Breast	348	174	129
Lung	296	132	116
Prostate	203	145	112
Stomach	81	53	34
Lymphoma	105	55	47
Non Hodgkins Lymphoma	82	47	41
Bladder	108	41	47
Melanoma Skin	91	36	35
Leukaemia	66	49	36
All Other Cancers	858	449	345

Table 4.2: Cancer incidence in the MWHB area by age group 1994-1998

Source: NCRI

CANCER	<18 yrs	18-65 yrs	>65 yrs
All Mlgnt Cancers	67	2037	2729
Colo-Rectal	0	228	414
Colon	0	136	249
Rectal, R'sigmoid Jn & Anal	0	92	165
Breast	0	420	231
Lung	0	196	348
Prostate	0	90	370
Stomach	0	52	116
Lymphoma	7	118	82
Non Hodgkins Lymphoma	2	92	76
Bladder	0	69	127
Melanoma Skin	1	94	67
Leukaemia	22	53	76
All Other Cancers	37	717	898

Table 4.3: Total number of cancer deaths in the MWHB area by age group
1994-1998

Source: NCRI

CANCER	<18 yrs	18-65 yrs	>65 yrs
All Mlgnt Cancers	15	991	2196
Colo-Rectal	1	119	276
Colon	1	89	224
Rectal, R'sigmoid Jejemum & Anal	0	30	52
Breast	0	139	142
Lung	0	182	413
Prostate	0	26	195
Stomach	0	46	110
Lymphoma	0	44	62
Non Hodgkins	0	38	57
Bladder	0	7	65
Melanoma Skin	0	7	12
Leukaemia	7	24	62
All Other Cancers	7	397	859

Table 4.4: Total number of cancer deaths in the MWHB area by county 1994-1998

Source: NCRI

CANCER	LIMERICK	CLARE	N.TIPP
All Mlgnt Cancers	1672	864	666
Colo-Rectal	213	110	73
Colon	175	77	62
Rectal, R'sigmoid Jej & Anal	38	33	11
Breast	151	75	55
Lung	340	127	128
Prostate	94	72	55
Stomach	69	51	36
Lymphoma	54	33	19
Non Hodgkins Lymphoma	49	29	17
Bladder	45	11	16
Melanoma Skin	11	4	4
Leukaemia	46	23	24
All Other Cancers	649	358	256

Morbidity and mortality of non-malignant disease in the MWHB area

Though palliative care services to date have focused on patients with cancer, non-cancer patients are also accepted by the service. The non-cancer conditions seen in this setting include AIDS, Motor Neurone Disease, Multiple Sclerosis, Renal Failure, Pulmonary Fibrosis, Respiratory Failure, Cardiac Failure and Peripheral Vascular Disease. The need for palliative care services for non-cancer patients particularly those with advanced respiratory and cardiac failure are now acknowledged. The estimation of the proportion of these patients who potentially require palliative care services is difficult for several reasons:

- The dearth of morbidity data.
- The means by which disease is recorded and consequently classified on death certification.
- The difficulty with timely and appropriate identification of the non-cancer patient who has a palliative care requirement.

It is thought, however, that the inclusion of non-cancer patients may double the requirement for palliative care services in this country.

The estimation of the number of non-cancer patients with a palliative care requirement in the MWHB area is based on UK experience, as were those used in the Report of the National

Advisory Committee. Higginson estimates that in a population of one million, 6,900 deaths each year are due to progressive non-malignant disease. A Regional Study of Care for the Dying in the UK found that almost one fifth of non-cancer patients had symptom severity comparable to the top one-third (in terms of symptom severity) of cancer patients. Patients with cardiovascular and respiratory diseases made up the bulk of these non-cancer patients requiring palliative care.

Extrapolating from these estimates, in the MWHB area where the population is 317,069 (based on 1996 census data), there are 2,188 deaths each year due to progressive non-malignant disease, and 438 of these should have a recognised period where they could benefit from specialist palliative care services. In the literature there is significant difficulty in determining the prognosis of patients with non-malignant conditions and hence in referring to a palliative care service.

Demography and Population Projections for the MWHB area

The population of the Mid-Western Health Board region was 317,069 at the time of the 1996 census. This represented a 2% increase on the 1991 figure. Figure 4.1 shows the age and sex structure of the population. Figure 4.2 shows the projected rise in the Irish population over the 30 years from 1996 to 2026. It is estimated that the population will rise by about 12% over that period. The most noticeable feature is the increase in the number of older people and the relative fall in the number of children. While the population and the birth rate of the Mid-West continues to increase, the relative number of those aged 18 or less is decreasing owing to the rapid drop in birth rate experienced in the 1980's. This is in line with national trends and may be seen in Figure 4.3.

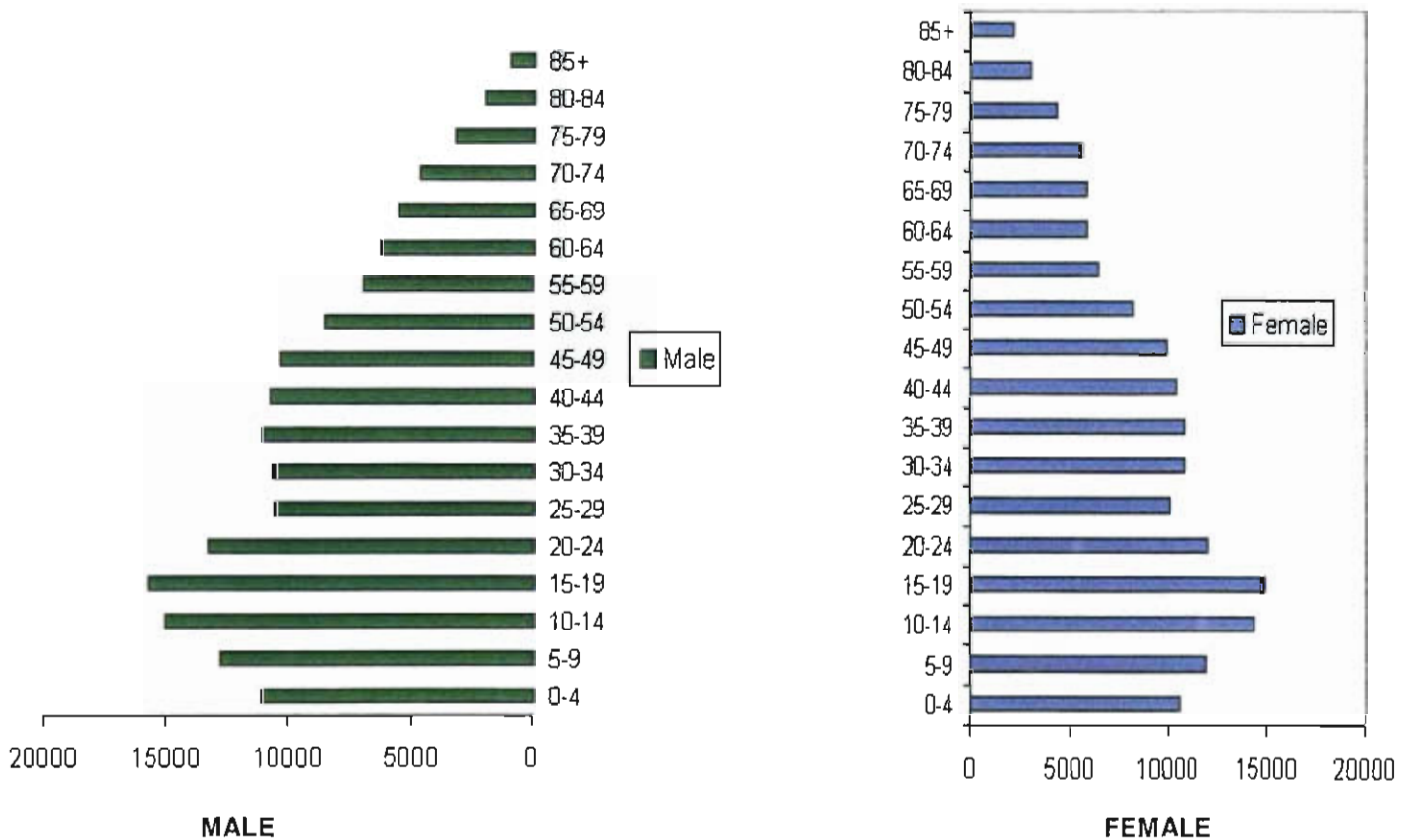


Figure 4.1: Population pyramid of the Mid-Western Health Board population, 1996 census

Source: CSO, 1996

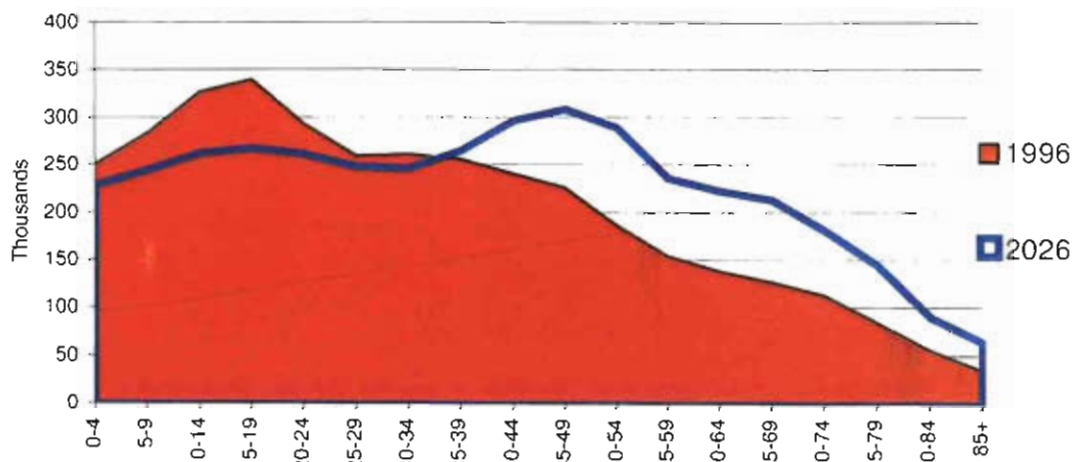


Figure 4.2: Actual and Projected National population 1996-2026

Source: Central Statistics Office

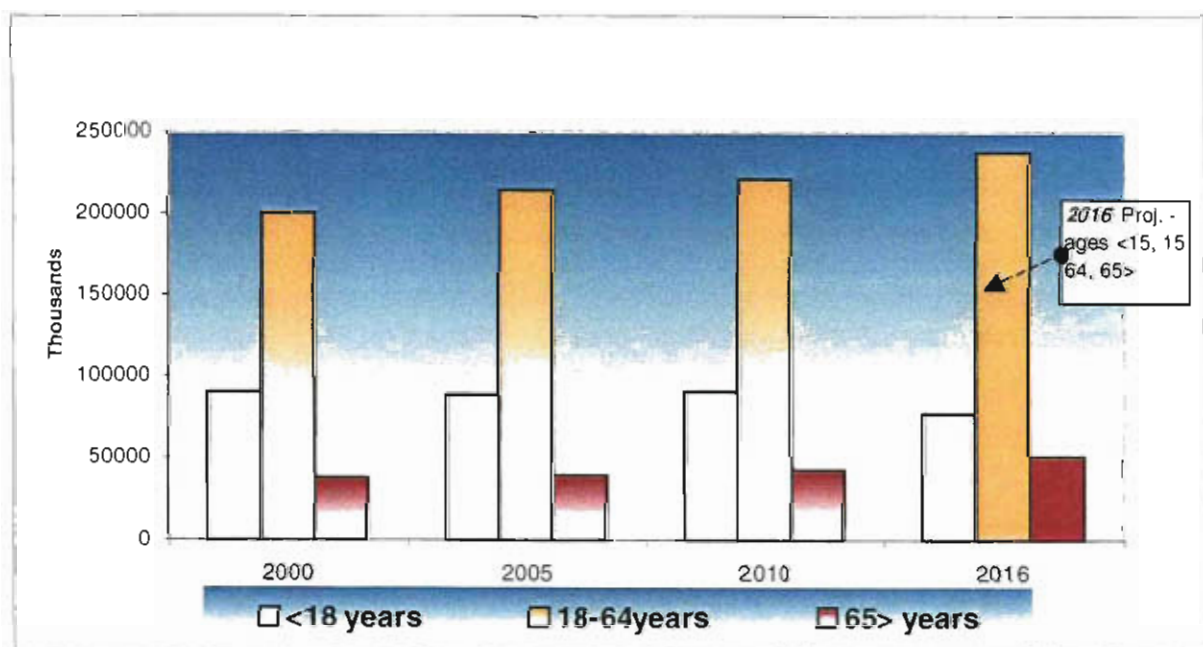


Figure 4.3: MIF2 projected population by age group for the MWHB area 2000-2016

Source: Central statistics Office

Using population projections the NCRI have predicted the number of cancer deaths in each age group for the MWHB and each county within the Board for 2005, 2010 and 2015, Tables 4.5 & 4.6.

Table 4.5: Projected cancer incidence in the MWHB region by age group 2000-2015

Source: NCRI

Cancer	< 20 yrs	20-65 yrs	> 65 yrs
2000	11	441	581
2005	6	518	608
2010	1	579	665
2015	0	622	777

Table 4.6: Projected cancer incidence in the MWHB area by county & age group, 2000-2015

Source: NCRI

CANCER	2000	2005	2010	2015
LIMERICK				
< 20 yrs	2	0	0	0
20-64 yrs	240	284	320	345
> 65 yrs	305	332	378	459
CLARE				
< 20 yrs	6	8	10	12
20-64 yrs	114	136	154	167
> 65 yrs	18	59	95	131
TIPP-N				
< 20 yrs	3	2	1	1
20-64 yrs	88	99	107	111
> 65 yrs	145	180	227	301

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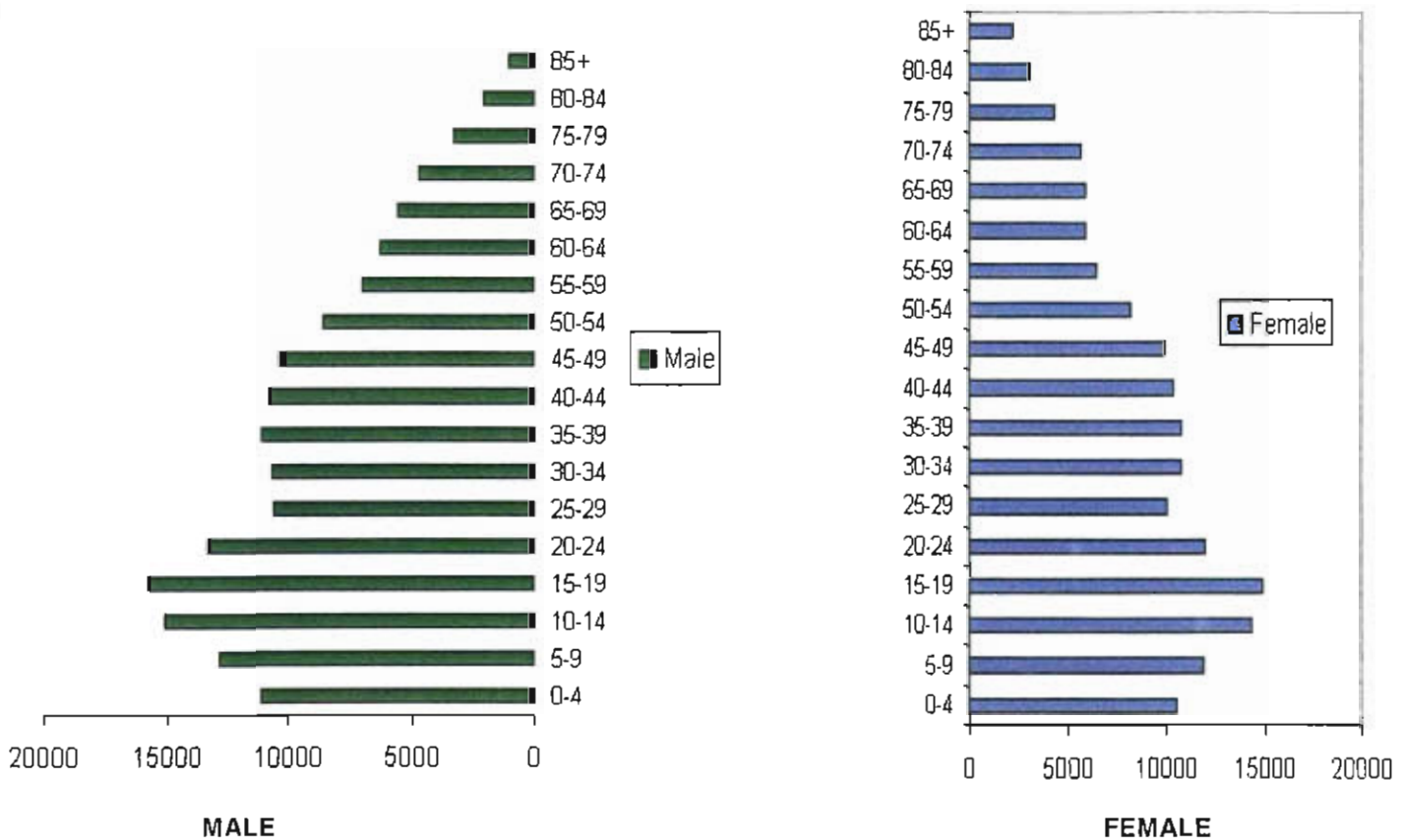


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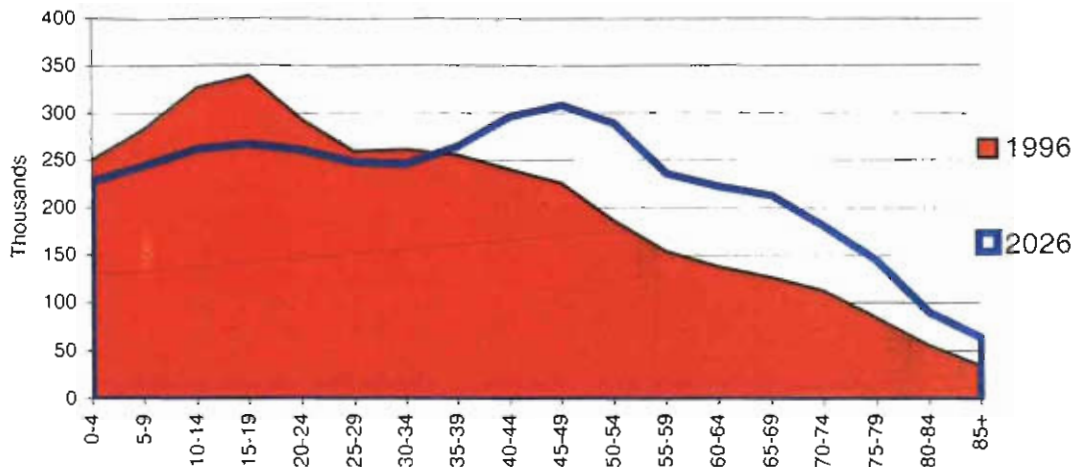


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Source: Central Statistics Office

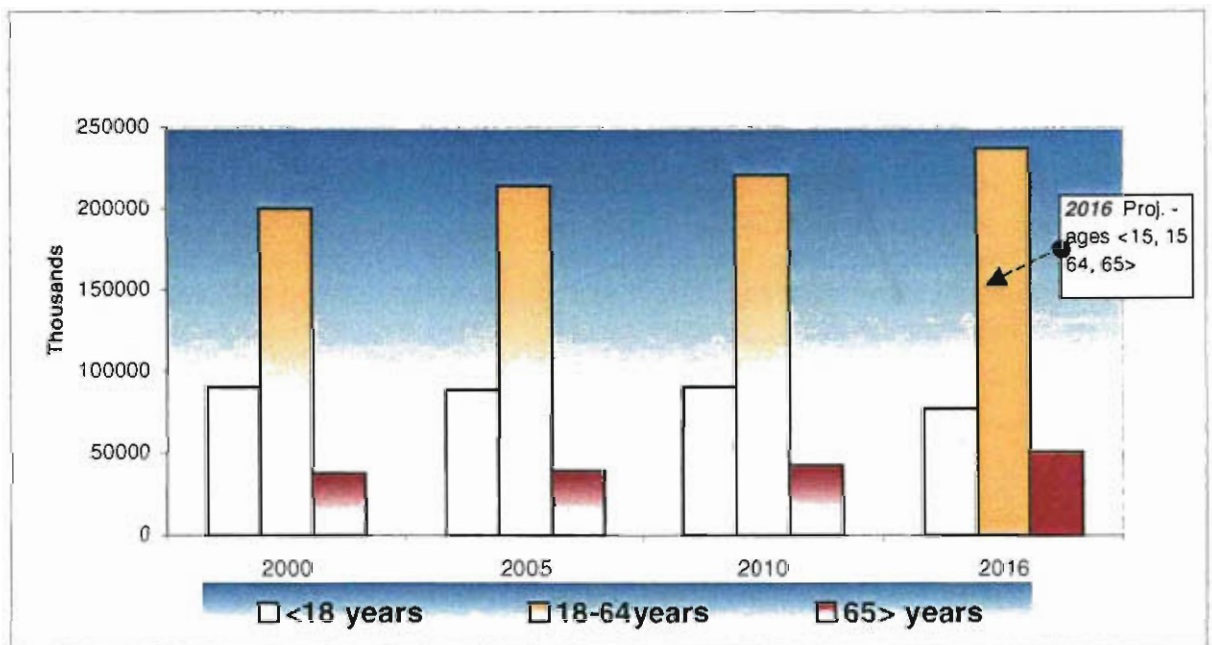


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< 20 yrs	3	2	1	1
20-64 yrs	88	99	107	111
> 65 yrs	145	180	227	301

Chapter Five

Palliative Care Service Provision and utilisation in the MWHB area

Specialist Inpatient Unit

The Little Company of Mary sisters identified the need for Hospice care in 1977 and a small number of beds were set aside for hospice care in Milford Nursing Home. The first purpose built hospice in Ireland, a 20-bed unit was built on the same site in 1983. Milford Hospice has worked in partnership with the MWHB since 1989 to provide hospice care for the region and 1999 marked the opening of a new 30-bed Specialist palliative care unit at Milford Care Centre.

The unit serves the entire Mid-West region and takes referrals from a variety of sources, General Practitioners (GPs) and Hospital Consultants.

There is 75% bed occupancy of the 20 beds in use, this is accepted as the upper limit of activity which allows such a unit to respond to service needs. The average length of stay is seventeen days.

The range of services offered to patients includes 24 hour nursing and medical care, Pastoral Care and Counselling, Physiotherapy, Occupational Therapy, Art and Music Therapy, Aromatherapy, Beauty Therapy and Chiropody and Social Work. A Consultant in Palliative Medicine took up post in January 2000. The Centre also fulfils an educational role with two dedicated education officers.

The service is funded by a combination of:

- State funding (MWHB)
- Voluntary donations and fundraising
- North Tipperary Hospice Movement/ Irish Cancer Society (ICS)

Admissions rate to the specialist inpatient unit at Milford Care Centre have risen steadily in recent years peaking at 322 admissions in 2001. Over two thirds of these admissions were new admissions with one third of patients being admitted to the unit more than once, Figure 5.1. Referral to the unit is accepted from GPs and Acute Hospital Consultants, Figure 5.2.

Admissions to Milford Hospice (1989-2001)

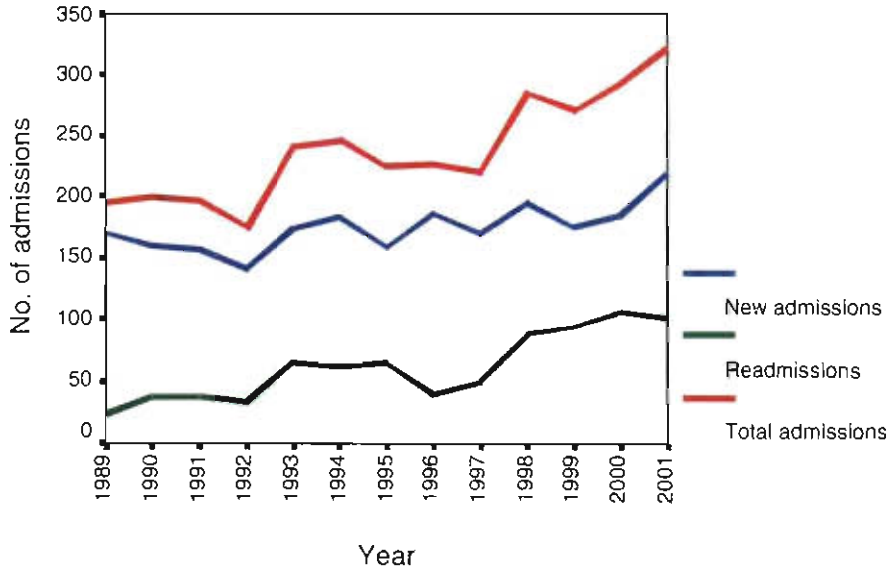


Figure 5.1: Admissions to the specialist inpatient unit at Milford Care Centre 1989 – 2001

Source: Milford Care Centre

Hospice referrals by specialty (1989-2001)

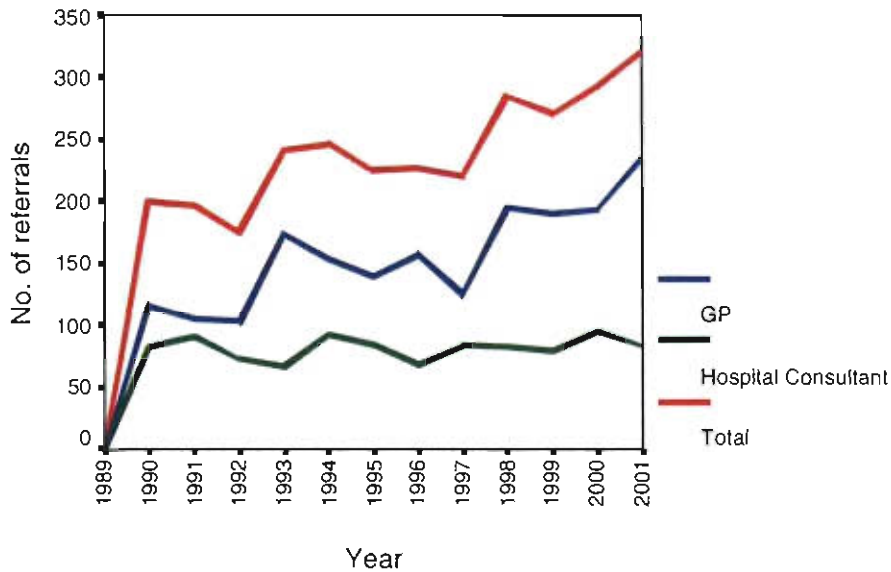


Figure 5.2: Referral to the specialist inpatient unit at Milford Care Centre, by specialty 1989 - 2001

Source: Milford Care Centre

Referrals are accepted from throughout the MWHB though the majority of patients are from the Limerick area, Figure 5.3.

Hospice Referrals by geographical location (1989-2001)

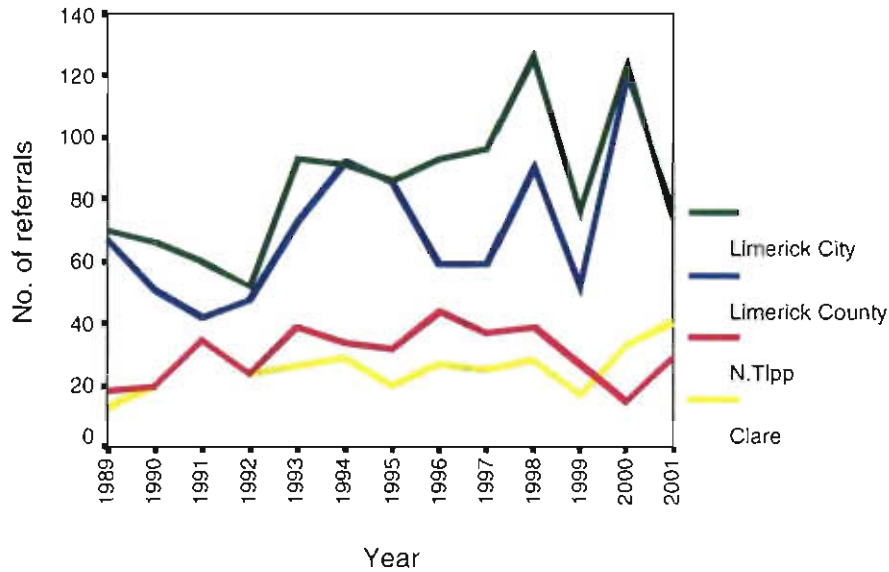


Figure 5.3: Referrals to the specialist inpatient unit at Milford Care Centre, by geographical location, 1989 – 2001

Source: Milford Care Centre

As illustrated in Figure 5.4 the proportion of patients discharged from the specialist inpatient unit, relative to those dying there, has increased steeply in recent years. This coincides with the increasing number of palliative care patients dying at home under the care of the Home Care Service, Figure 5.5, and this reflects the increasing workload of the Specialist Palliative Care Unit team in providing rehabilitation, symptom control and planning discharges.

Deaths and discharges from Milford Hospice (1989-2001)

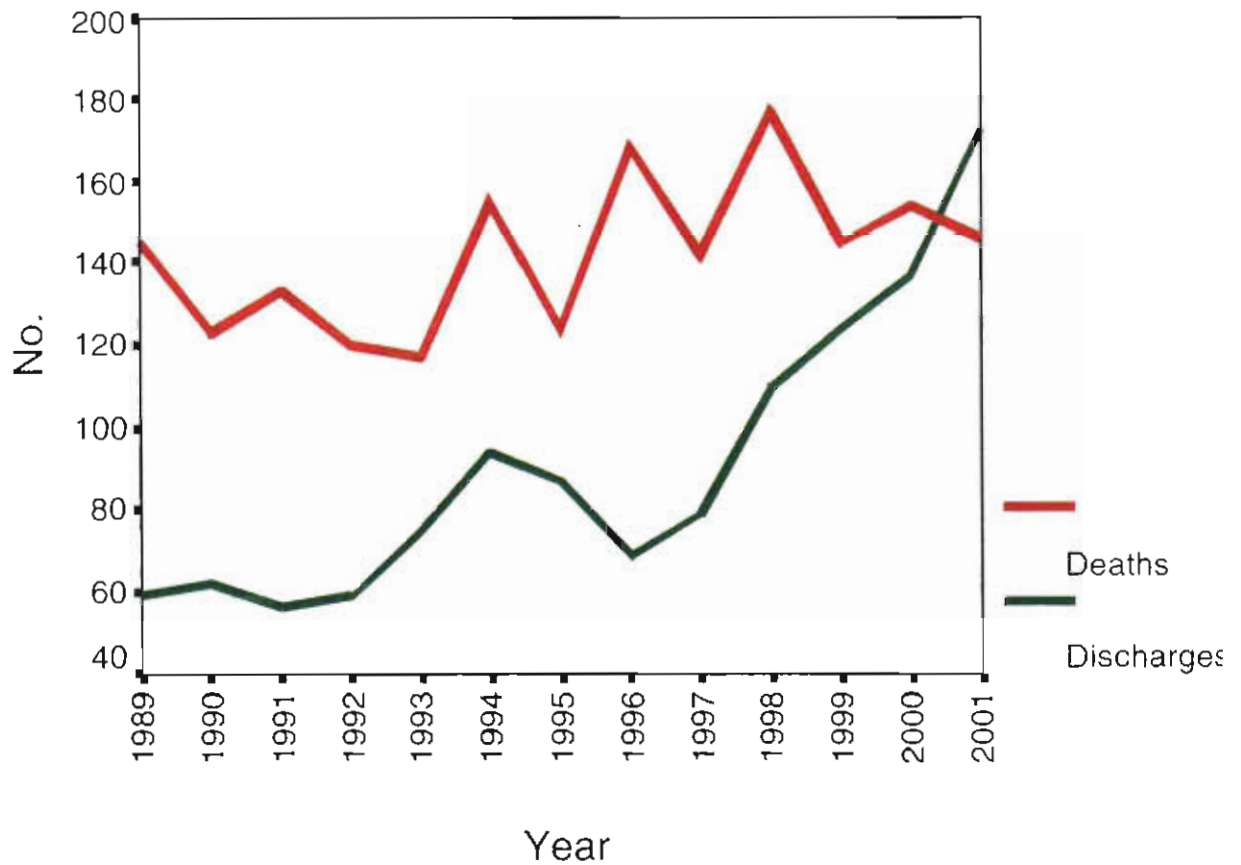


Figure 5.4: Deaths and discharges from the specialist inpatient unit at Milford Care Centre 1989 – 2001

Source: Milford Care Centre

Home Care Services

Specialist palliative home care services, coordinated from Milford Care Centre to cover the entire Mid-Western Health Board Region consist of 13.75 Home Care Nurses, including a full-time co-ordinator. Nurses covering the greater Limerick City area are based at Milford Care Centre (n=7.5) and there are 5 other nurses located throughout the remainder of the Health Board area (one in Nenagh, one in Thurles, three in Ennis and one Newcastle West).

In 2001 there were 488 referrals to the service, the geographical breakdown of which is seen in Figure 5.5. Hospital Consultant referrals to Home Care dropped in 1999 and increased again slightly in 2001, Figure 5.6.

Home care referral by geographical location

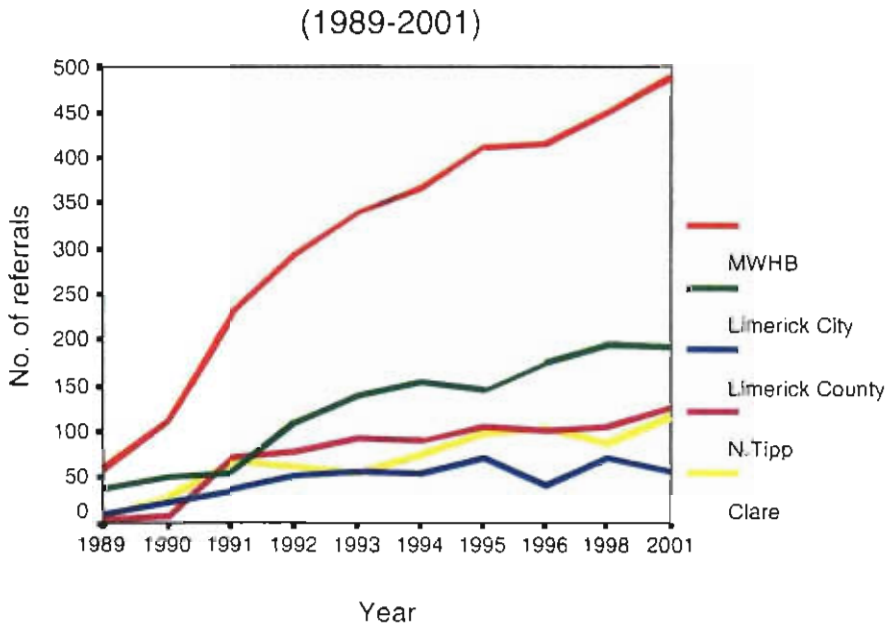


Figure 5.5: Referrals to home care by geographical location, 1989-2001

Source: Milford Care Centre

Home Care referrals by specialty (1989-2001)

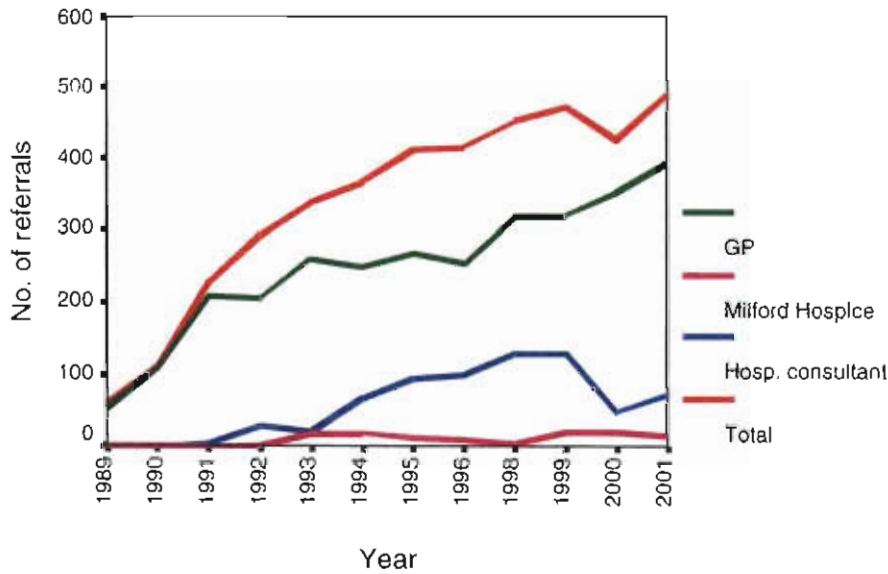


Figure 5.6: Referrals to home care by specialty, 1989-2001
Source: Milford Care Centre

Referrals to the Home Care service continue to increase and indeed have outnumbered the admissions to the specialist inpatient unit since 1991. This trend is illustrated in Figure 5.7.

Admissions to Milford Hospice & Referrals to Home care Services (1989-2001)

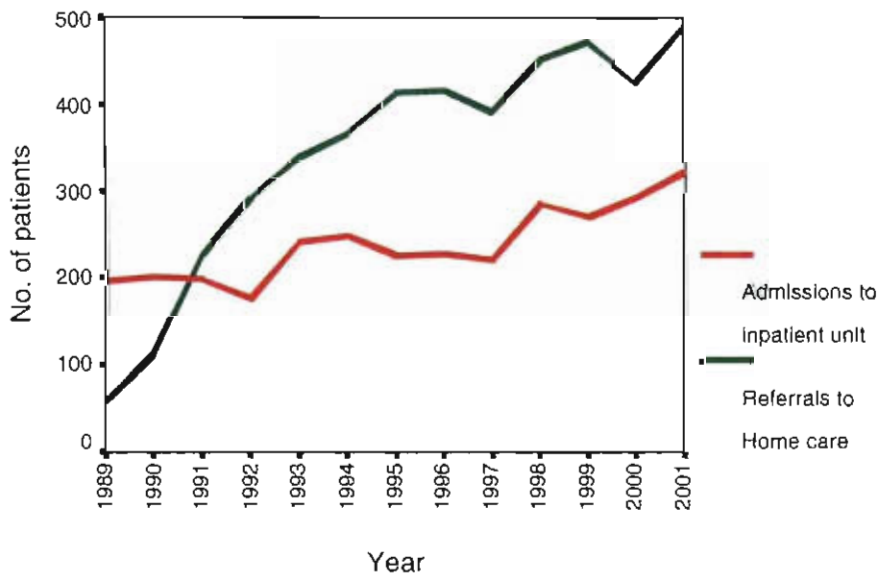


Figure 5.7: Referrals to home care and admissions to the specialist inpatient unit 1989 - 2001
Source: Milford Care Centre

While most patients referred to this service die at home, the number of home care patients dying in hospitals, the specialist inpatient unit and nursing homes is also on the increase, Figure 5.8.

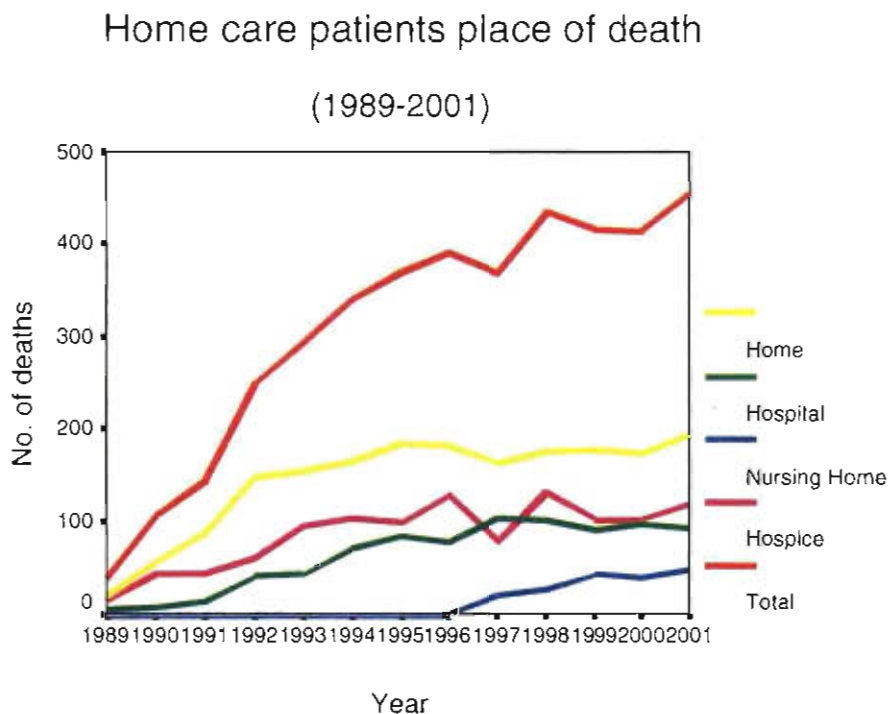


Figure 5.8: Place of death of home care patients 1989 - 2001

Source: Milford Care Centre

Night nurse services are provided by the Irish Cancer Service. Nurses must be accessed locally usually by a member of the specialist palliative care service, and be on the “live nursing register”. The ICS funds this service up to a maximum of five nights per patient. In North Tipperary the North Tipperary Hospice Foundation provides additional funding for night nursing while everywhere else alternative arrangements have to be made.

There is no specialist community physiotherapy or occupational therapy service. Palliative care patients requiring these services access them through community care and though treated as priority cases, which guarantees assessment within two weeks, many patients either die or are admitted to hospital/hospice while waiting. Except for North Tipperary where the North Tipperary Hospice Foundation operates a service, problems similar to those encountered with ancillary services are experienced in obtaining specialist equipment.

Acute Hospital Specialist Palliative Care Services

There are four acute general hospitals in the Mid-Western Health Board region:

- Mid-Western Regional Hospital Limerick
- Nenagh General Hospital
- Ennis General Hospital
- St John's Hospital

There is an acute palliative care service in each hospital, which is nurse led in all but the Mid-Western Regional Hospital, where, since January 2000, the MWHB Consultant in Palliative Medicine has three sessions per week. The Consultant and Non-Consultant Hospital doctors in Palliative Medicine in educational programmes in the MWRH as well as organising an International Conference on the development of palliative Medicine held in April 2002 in the MWRH. Such developments are necessary to maintain the service as a recognised post for Specialist Registrar Training. Paramedical services are accessed via the general acute hospital service, therefore in three quarters of the acute hospitals in the MWHB the specialist palliative care team consists of a nurse.

The palliative care service in the acute hospital setting is holistic in approach to both patient and relatives and encompasses:

- Assessment,
- Pain and symptom control,
- Care of those imminently dying,
- Referral to other palliative care/non-palliative care services –e.g. Homecare, Community services etc.
- Psychosocial support
- Staff counselling
- Staff education.

There were 530 referrals to this service in 2001. Almost 50% of these were generated in the Board's largest hospital – The Mid-Western Regional Hospital, Dooradoyle, Limerick. However, referral rates in the outlying hospitals is also high, especially relative to the size of these hospitals, with the exception of St. Johns Hospital where the service is only in operation since 2001, Figure 5.8. (Specialist post filled from August 1999 - January 2000, post then became unoccupied until October 2001)

Acute Hospital bed numbers and referral to palliative care for 2001

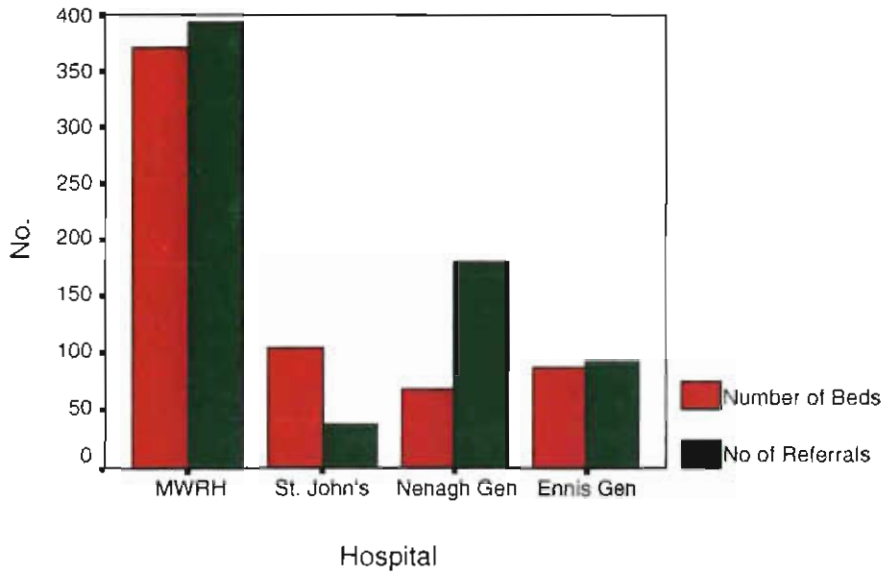


Figure 5.9: No. of referrals to acute hospital specialist palliative care services relative to hospital size for 2001

Source: The acute hospitals of the MWHB region

The majority of patients seen in acute hospital palliative care setting in 2001 had cancer but non-cancer patients were also seen, Figure 5.9. Non-cancer patients suffered from a range of illnesses including:

- Congestive Cardiac Failure (CCF)
- Chronic Obstructive Pulmonary Disease (COPD)
- End Stage Renal Failure (ESRF)
- Pulmonary Fibrosis
- Osteoporosis

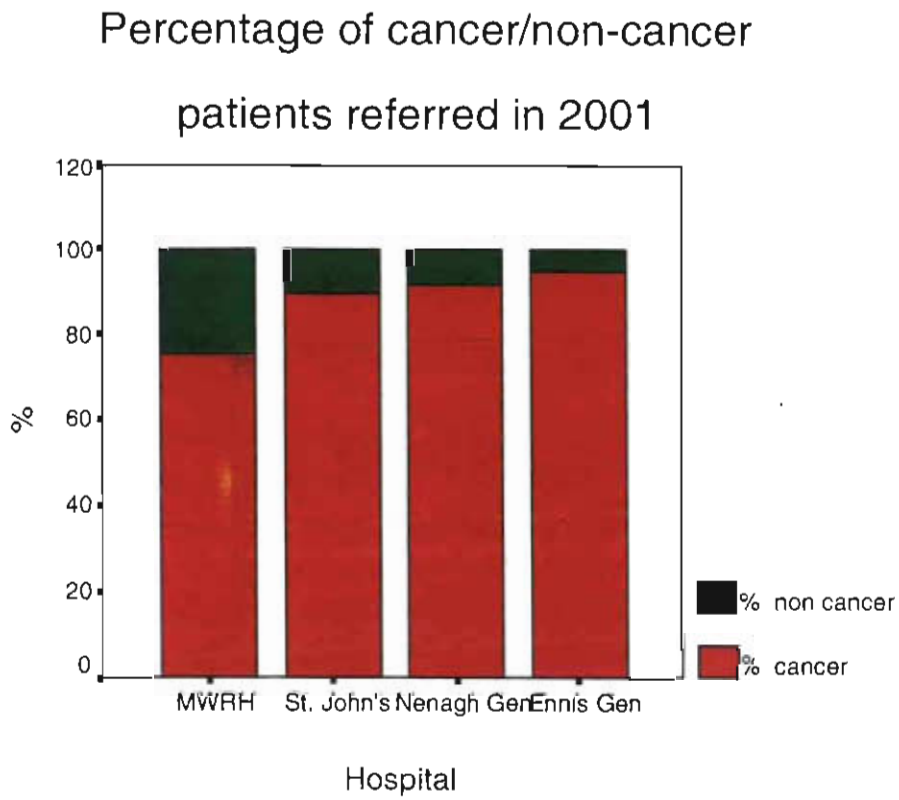


Figure 5.10: Percentage of cancer and non-cancer patients referred to the acute hospital palliative care service in 2001.

Source: The acute hospitals of the MWHB region

Support Bed Units

There are seven community hospitals in the MWHB area providing dedicated palliative care beds as shown in Figure 5.11. Almost all of these units are undergoing development at the present time palliative care having been provided within general wards in the past. In the case of two Clare hospitals and one North Tipperary hospital these dedicated beds have not yet been officially opened.

Referral to these units is via GPs, acute hospitals and the specialist palliative care service. The vast majority of patients admitted to these units are cancer sufferers with some units (n=3) accepting cancer patients only. The age profile of patients is elderly with a median age of 71 years, though patients as young as 38 have been admitted. With the exception of Cahercalla community hospital, which has seven dedicated palliative care beds, each unit comprises a two-bed unit with dedicated family room/area and tea making facility. Medical care is provided exclusively by GPs and local home care nurses provide specialist palliative care input. The number of admissions to each of these designated palliative care bed units is shown in Table 5.1.

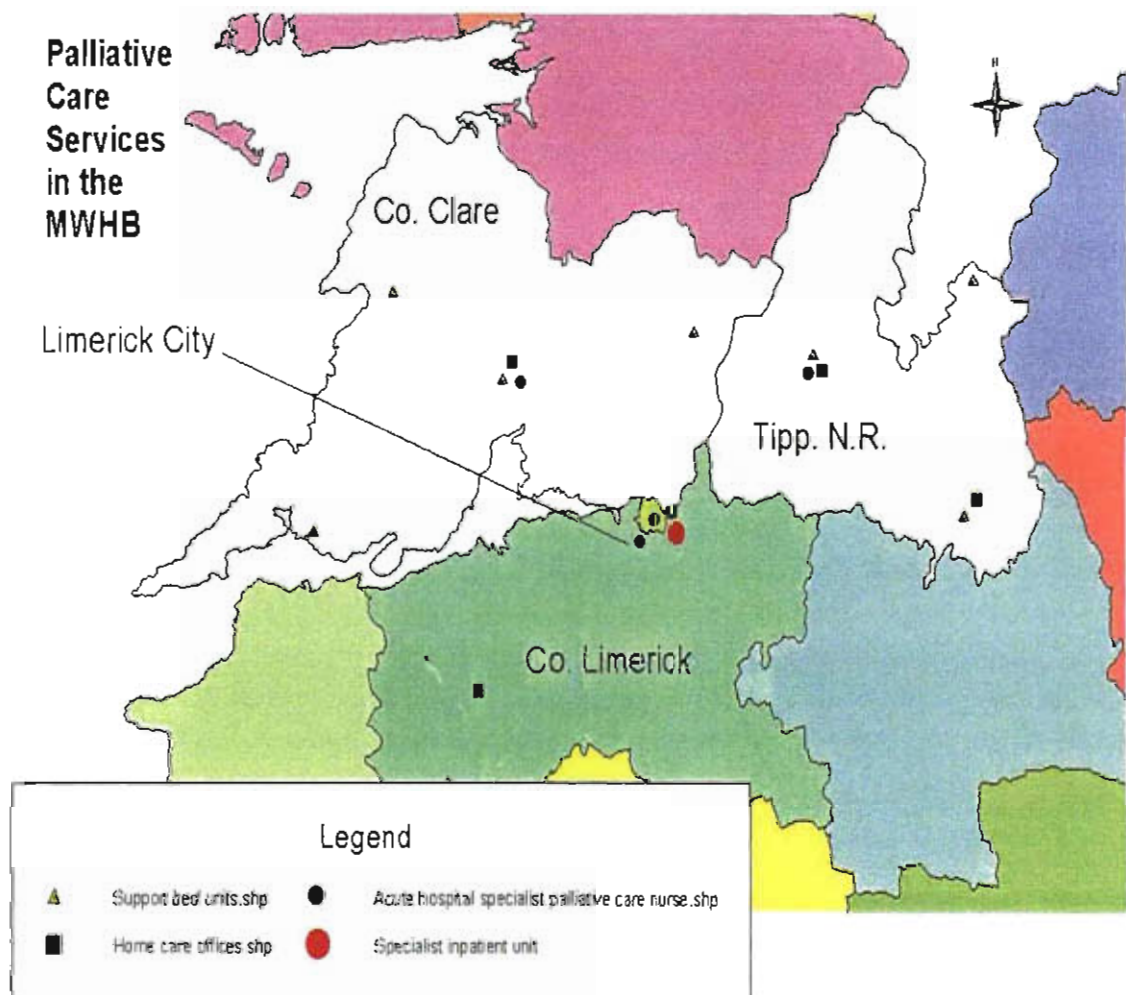


Figure 5.11: Location of palliative care services in the Mid-West

Source: Milford Care Centre

Table 5.1: Admissions to support bed units for 2001

Source: Milford Care Centre

Support Bed Unit	No. of Admissions (2001)
Roscrea	31
Thurles	11
Nenagh	5*
Ennistymon	8**
Kilrush	0***
Raheen	0****
Cahercalla	56

* Unit open for 2/12 only

** 1 bed open in 2001

*** Unit not open in 2001

**** Unit not opening 2001

Day Care Services

Specialist palliative care Day Care services are based on the ground floor of the Milford Care Centre. Though within the same building and though it accepts referrals from the inpatient unit it is run separately. Patients receive medical attention from their own GPs in the home setting and not from the consultant led service of the inpatient unit.

Nursing staff complement consists of a nurse manager and one full time staff nurse supported by three point five care assistants. Complementary /beauty therapy is also available and ancillary services such as physiotherapy, occupational therapy and social work may be accessed through the Care Centre as required.

The Centre can cater for up to twelve patients at any one time and sessions are run twice weekly, (Thursday and Friday). The unit received 44 referrals in 2001 and had a total of 491 attendances and is therefore functioning at 50% of maximum capacity.

Specialist Palliative Care Activity for 2001

Activity levels based on the numbers of admissions and referrals to all sectors of the service are summarised below in Table 5.2.

Table 5.2: Admissions and referrals to specialist Palliative Care Services for 2001

Source: Milford Care Centre

Service	No of Admissions/Referrals
Specialist Inpatient Unit	322 Admissions
Home Care Services	488 Referrals
Acute Hospital Specialist Palliative Care Services	630 Referrals
Support Bed Units	111*
Day Care Services	44 Referrals (491 Attendances)

** Not all support bed units were fully operational in 2001*

Chapter Six

Qualitative Research Results

The qualitative findings of this study are presented to describe the experiences and views of patients and their families as they journey through the different strands of palliative care service provision and are concluded with the views of service providers.

General Hospital Services

Hospital Care and Treatment

In relation to patients and relatives' views of the care and treatment they had received in hospital, a variety of cues were used in their assessment of the standard of care. These included the attributes of staff providing care, information and communication, as well as the involvement of family. In relation to the attributes of staff, their kindness, friendliness and support, and the reassurance staff offered were important. These attributes were manifest in the willingness of staff to inform both patients and their family about procedures and to explain the purpose of different treatments. Clear, honest, consistent and timely information throughout the course of care was valued and was interpreted strongly as a reflection of expertise and high standards of care.

"Now I understood from the word go that even though they never said no definitely no they practically said the chances of surgery after the radiotherapy were nil... They explained the whole thing they were very good now Dr----- was amazing in the sense that he had a lot of patients and he was explaining everything."

"In every hospital. I couldn't say a word about anything. I got the best of care."

"Absolutely, here I can't say enough about them here in the-----, the nurses know him very well because we have been up and down getting stuff for him and bringing him up if he had a blockage in the tube or anything we felt if there was anything he needed the door was open day and night for us. They told us that and I couldn't just say enough about them."

"I just couldn't say enough for here for -----and the nurses, the nurses there were just so kind to him, they are friends of his. I just couldn't say enough about them."

"Excellent, excellent, with the different doctors and different nurses and all the rest."

While some patients were impressed by the standards of palliative care provided by hospital services, others were less so. The lack of a willingness to listen to their complaints; the lack of detailed information about care and treatment; and lack of respect for individuality and privacy emerged as aspects of care in hospitals that fell short of expectations and led to much dissatisfaction. Among those who were

dissatisfied, staff were widely perceived to not *“have time for you”* and the lack of communication skills on the part of doctors was particularly emphasized.

“Now I found myself left in the dark a lot I really did. Even from the very first day I was diagnosed with cancer I found it hard to get answers. Now I know that it's very hard for doctors to give you answers. I know they can't tell you things because they don't want you to quote them on it but I did find it hard to get information out of them. Like say the day I was diagnosed the doctor said to me I think that you should get psychological help or you should see a social worker or something like that and nobody ever came back to me and told me how to go about doing it. I found that there was no help there at all...”

“Now I mean I pushed for answers myself I would have no problem asking questions but I did find it hard to get the answers that I wanted off them.”

“I mean like even when I was in the hospital there were nurses I was scared of and I couldn't ask them questions there was one particular nurse I was terrified of her and I was afraid to ask anything.”

“It was my first time in hospital ever like some of the nurses were really nice and some were rude, and I was like: how do they do it? I felt sorry for them actually and I felt sorry for the ones who were even rude to me because I knew that some of them were probably very nice people. They were just stressed out really and they had no time. They didn't have the resources.”

“In that hospital I found that I was afraid of some of the staff there and the consultants in there they were in and out in two minutes.”

“I was taken into a room and he told me and my mother was there with me. Now he was very nice but he wasn't able to give me any information about my cancer which I found hard because all I knew was that I had cancer and that it was malignant and that it was an aggressive form of cancer and I found that very upsetting that I wasn't able to get any answers. I was left for two days.”

“As ----- said herself when she came down from ----- she said if I was to go up there again even to see the next 10 years of my life I wouldn't. That's how bad it was.”

“That hospital I would say it would be classed as a concentration camp. That's my own opinion.”

The involvement of family was also an important cue that was used in the assessment of standards of care and families as well as patients wanted to be informed and actively consulted in care decisions. While some perceived the involvement of family in patient care to be adequate, others had found little or no involvement of family by hospital services. It is not clear, however, whether this resulted from patients own instructions not to involve relatives, or decisions made by hospital staff.

“Not alone that but she has another sister who is what I call a mad scientist and she used to be e-mailing Dr. ----and he was absolutely brilliant now with all the awkward questions.”

While information and communication needs were related to medical care and treatment, the importance of information about support services in the community and entitlements also emerged. In relation to the provision of such information by hospital services, the view was widely held that *'they tell you nothing in the hospital'*. While most patients using hospice services had been referred by the hospital, some had only found out about the availability of hospice services by chance.

"I phoned Milford myself."

"A friend of mine who works with the Irish Wheelchair Association suggested that I speak to someone in the Health Board, because it was just like that medical card, unemployment benefits, carer's allowance or that. I just didn't know what to do where to go, what were you qualified to get or not...then I was referred to a Community Welfare Officer, a local person, who again didn't have the same knowledge at all so I just gave up. I just go around and try and find out myself now. Again it's like I say every service is limited to the abilities of the person that's running the service if you know what I mean."

The Co-ordination of Hospital Palliative Care Services

Many participants shared the view that hospital service provision was characterized by a lack of co-ordination predominantly associated with the lack of continuity of care. In most interviews, discussion focused on the ever-changing team of doctors resulting in established relationships and point of contact with the system of care being abruptly severed.

"Things weren't coordinated, not at all, that's not very hard to see, agency nurses and people who might not have had a clue about that specialized nursing."

"There were a lot of unsatisfactory incidents."

Oh yes dangerous ones there for the patients I heard a nurse telling him I'm only here a fortnight I'm nervous...and she in charge of the tube."

"The weekend - very poor cover I didn't think there was anybody available doctors or otherwise."

"That's what I found wrong in -----as well. Agency nurses coming in and out they didn't know how bad you were or anything."

*"The doctors didn't really speak with each other they wrote to each another and so by the time secretarial and administration services caught up well then it was better for me because at least I was talking to all of them and I was bringing the story...
... I was able to understand their language to a good degree but I said to myself God help the person that could not do that co-ordination job. "*

Few participants had availed of hospital social worker services and of those who did the role played by the social worker in their care were in assisting with the organization of financial matters including the payment of rent and bills.

“ They had a Medical Social Worker who was fantastic to him he was on life support for 11 weeks and she used to check with me constantly and she organized a little grant for me through the hospital board.”

A suitable venue at the hospital for family members to meet the doctor in private was viewed as a fundamental need although such a facility was not always available.

“With regard to the privacy that the doctors would come in and just pull a screen around. And you would hear them talking all over the ward like you know.”

“The only one we were talking to was Dr.----- He called us out there to the corridor and we were talking in public and we weren't very satisfied with that.”

The Benefits of Specialist Palliative Care for General Hospitals

Participants who had had experience of hospital services with a specialist palliative care team consistently expressed the view that high standards of care prevailed and that service provision was well co-ordinated. Aspects of specialist service provision that were particularly valued were the co-ordinating and supportive role played by the palliative care nurse as well as the designation of a member of the medical team to each patient.

“Those two nurses I can pick up the 'phone on the days when I know they are there if we have a problem I'll say “this is what is happeningI gave him that but I can see all sorts of weird things happening here” and they would take the details and they would say “OK we'll speak to Dr.....and come back to you” and they would be back to me that day or the next day with a suggestion and we would work together.”

“That's the type of service I suppose that you need to have, you need the link person because I was ringing the neurologist's secretary, I was ringing this doctor's secretary, that doctor's secretary, sure those poor girls don't give adamn they are doing a job of administration they can't help you from a medical point of view so those nurses in between the consultant and the person they have workedand I heard it even on the TV that it has been a great service.”

Access to Hospital Palliative Care Services

A recurring theme in relation to the accessibility of hospital services was transport difficulties to and between hospitals. The physical exertion involved in the use of public transport to hospital appointments was a difficulty experienced by patients being cared for at home and often necessitated a family member taking time off work to drive them to the hospital. The inefficiency of transportation services between hospitals was also particularly emphasized.

“The only delay was when she went to the Regional Hospital for some x-rays and some scans. There was an Ireland match on the same day and she was sitting in the chair for seven hours waiting to be carried back to Milford. Her condition was

desperate so she was very agitated. The boys probably popped in to watch the match!?"

"You wouldn't mind if you were just sick like a normal person but when people are terminally ill its so bad it seems cruel even to pass them there but to have them waiting..."

"The discomfort of it. (The ambulance).... it was terrible."

"Transport yes. It was the worst. Transport was bad. It was very uncomfortable."

"We travelled up and down in the car you know and only for her (mother) I don't know how I would have managed it. I don't know. A lot of neighbours offered to take me but I still don't know how I would have managed to do it. That would be a big problem for a lot of people."

"Now we had to travel up and down to Cork for that as well which is just tough going..... you know she was up and down she spent six weeks sitting in the back of the car she used to sleep in the car up and down and really that was quality time for her that we were spending driving up and down in the car."

"There was a delay there you know from the time she was referred to the consultant to the time that he took her in..... That was the worst time for me because there was two nights that she was at home and I was actually rocking her trying to get pain relief."

Hospice Service Provision

Since most respondents had had experience of varying strands of hospice services, many of the issues, which emerged from analysis of the data relating to hospice services, were appropriate for inpatient, day care, and home care services. The findings are thus presented for hospice services in general with specific issues raised in relation to other strands of the service presented separately.

Access and Equity

Access to inpatient hospice services at times of crisis for symptom control was widely viewed as occurring without undue delay. A recurring theme in relation to access to inpatient hospice services was the personalized and reassuring manner in which patients were reminded that their bed was always ready for them should they need it.

"I phoned Milford and asked them to get involved and that very day they came out."

"I can't remember how I found out about the hospice I think it was my GP might have told me to get in touch with them and I rang them and the following day the home care nurse came out to me and the doctor and from then on it was just fantastic."

“Just for me to know that if things got so bad that I couldn't cope would he be able to go in for a few days for him to rest after it and for me just to get myself together so that I could cope with the next phase so she did say that that would be a possibility.”

Care and Treatment

The view was widely shared among patients and family members that the care and treatment received in hospices was of a high standard and superior to that received in hospitals.

“She had the best of attention from Milford from the start.”

“The catering staff are brilliant and I mean even down to the cleaning staff they are lovely from the cleaning staff up to the highest doctor they all have been very very nice.”

“I would love sometimes when I come in here I'd be so angry and I would love to be angry at the nurses or at anybody and I would say I wish they would do something but every single person that I have come across here that I have dealt with have gone out of their way to relieve-----'s pain and from the word go that's what they're doing and they are still doing it.”

Communication in hospices was felt to be better than in hospitals and hospice staff were widely judged as having 'more time' for both patients and family. They particularly valued the willingness of staff to offer information and explanation and to demonstrate a supportive and caring attitude.

“There is not one nurse here who has been unkind. It is like they have been hand picked. Now I would have to say in their defence they have an awful lot more time on their hands in the sense that they had a lot of time to sit down and talk to me, whereas I know in the public hospital they just don't have that time, so a lot of the time it wasn't necessarily the nurses' fault. They didn't have the resources and they didn't

have time to talk to patients either, it wasn't necessarily personalities either that you know they had bad personalities and the staff in here have good personalities. I know the staff in here have an awful lot more time to come in here talk to me and sit down and even just pass a bit of time of day with me if they wanted to or if I wanted to talk to them. There wasn't a rush on them.”

“I have to say they look after every side. I mean even the other day, say I have been here nearly three weeks now, and the only day that the doctor doesn't come in they come in every morning except I think Saturday morning and a team of them comes in there would be two doctors and a nurse at least and they do the rounds every morning basically finding out how you are getting on which I think is great because it means your pain your needs are being updated daily basically.”

The high standard of hospice services was also manifest through staff responding to the needs of patients and their family in a kind and friendly manner. Both patients and relatives were very satisfied with the level of information received from all staff.

“They told me if my medication was changing why it was changing. The other thing about communication I found which I thought was brilliant was my mother is very involved in my care and she is a nurse herself and she’s nursing me throughout my illness like at home she’s been fantastic and I think she loved the fact that they wanted to have meetings with her not only did they tell her when they would bump into her but they arranged to have meetings with my mother, with my sister anyone who was around anyone who was interested even my 21 year old brother who wouldn’t have an awful lot to say you know he wouldn’t have opinions but they were mad to include him in anything that was going on and that was very important to my mother that he was included.”

“I mightn’t meet the doctors all the time but----- what she said one day and I thought that’s really what this place is all about... She said they had a meeting - in the room - and she was at the meeting discussing her pain management and she said that was really nice. She was deciding and they did that all the time from the start they said it isn’t they who are deciding she will be deciding with them and she has done.”

In addition to the high standard of medical treatment and care provided by hospice services, the availability of physiotherapy and occupational therapy, the social worker, hairdressing, and aromatherapy were equally valued services for their benefits to health and well being.

“The arts and crafts are great for him, I can see that. It’s really been good for him he is enjoying it, he has done beautiful things.”

“The social worker I would say she was able to sense that -----didn’t want to get in to deep conversations with her about life or death or anything... I suppose she would have the training to know.”

“They offered me aromatherapy, I did do the aromatherapy and they have a room downstairs basically for mediation with tapes etc, it’s fantastic.”

While some participants felt that they were adequately supported by the hospice services, others felt there was room for improvement or development of more services and night staff.

“You see if the nurses or doctors in Milford had explained it, had said this could happen it would put you wise to it... Give some sort of advice I know they can’t really tell what way because people die differently. They can’t say this is going to happen this way or that way. If you just had an idea of all the things that can happen and what to expect.”

“I have a swollen leg and because I was having radiotherapy treatment in Cork I had to go down five days every week and I used to incorporate my lymphoedema massage for an hour after that and she was a fantastic nurse but there are only fifteen qualified lymphoedema nurses in Ireland so there’s none in Limerick. If only there were more lymphoedema nurses.”

“The only criticism I would have at Milford would be the staff was so small at night, I mean they couldn't think of everyone at night.”

“ In Milford I slept in the chair. Even during the night-time the nurses couldn't keep coming every time we rang the bell she was very sick and if she wanted it she wanted it now so I decided it was better for me to be there if she needed small little things.”

The Hospice Environment

While many patients had had preconceived notions of the hospice as a depressing place of death and were initially reluctant to avail of the service, their fears were soon dispelled by an environment that was widely described as ‘beautiful’, and ‘more like a hotel’.

One respondent who had been an in-patient in Milford Care Centre and a support bed unit summarized her views of the service as follows:

“Ah, sure its heaven on earth, heaven on earth, and when 'twas first mentioned I said I'm not going to that place...you have daily mass, your surroundings and food are like a hotel...People on the outside haven't a clue the wonderful work that's going on by the nurses and doctors in the place. I'm not able to describe it.”

Hospice Day Care

Day Care services were viewed as an invaluable service that provided an important opportunity for social contact resulting in an increased sense of well being.

“I found the Day Care Centre was fantastic. They were genuinely concerned about all his needs.”

“I know somebody said if we could talk to Milford because... they might be able to help with some physiotherapy and at the time too needless to say I was caring for him and I was getting no break and somebody suggested Day Care. I wish I could remember because they were our lifesaver obviously as well. It was fantastic.”

However, participants expressed disappointment at the unavailability of palliative day care services in Co. Clare and North Tipperary. The only palliative Day Care service available at the moment is on a Thursday and Friday in Milford Care Centre and serves patients living within a ten to fifteen mile radius of the Centre.

While Day Care services were viewed as a valuable resource, the findings also indicate that a gap in hospice service provision exists at the level of psychosocial care of the patient. Although the emotional and psychological benefits of social contact with others suffering a similar fate were emphasized, there was a shared view that staff had a limited awareness of the complexity of patient's lives with calls for an increased emphasis on psychosocial care.

“There was one thing now though again I found the psychological side of it though there was a service offered at the Centre we did try it but unfortunately the particular person although a lovely lovely person probably very knowledgeable but the

relationship didn't develop so I felt he wasn't really counselled in any shape or form and in my opinion to this day has never had proper counselling."

Nursing care was unanimously viewed as excellent.

"I knew----- was very upset for me you know her empathy was great, really great and it was she who suggested that maybe if the Care Nurse came to visit would that be a help to me and that I would have someone to talk to and that she would be able to liaise with the doctor at Milford and that she also might be able to help. "

"----- Is great she has a great eye for seeing whether you are well or you are not well and in her own nice way she gets things done."

Transportation to the Day Centre didn't prove to be a problem.

"I took him out I think the first one or two times and after that the bus picked him up. They would pick him up and drop him off that was just fantastic."

A strong view emerged in the analyses that the Day Care services could be improved with more staff and a more holistic approach of care delivered to the patient.

"The service is definitely lacking and they have every facility for it but there is no manpower to do it...I. think that there isn't enough for palliative care here because what is here isn't suitable because people like me and people who are coming here we are all the same, we require a holistic approach you know our whole being needs and where the client is put first and their needs are taken into account and that is not happening here because there is nobody as far as I know qualified to do that."

"They haven't the manpower. There are no treatments, no massaging, and proper massaging, there is the beautician here but I feel she is only going in for the beauty but who wants beauty? It's lovely but if you need things more I would go for the priorities rather than beauty you know the essential needs like reiki massage, and reflexology."

"The day it's not organized because you could be sitting in there for hours and there would be nothing to do."

"If they had personnel who would do reflexology, medication, reiki massage, relaxation therapy, stress management all those things and they have the facilities all they want is personnel and somebody who would be committed to it because there is no commitment now I am sad to say it really. I say that with a heavy heart. They could organise it better I feel there is no organization."

"Actually somebody that would be good at management and organising who would see that people would get a certain amount every week or every second week if they haven't the facilities to give me what I want, well what do I want? What I need this week well that I would be sure to get it next week. I couldn't see anything wrong with that like this week you don't get X, Y, Z but next week you will get X, Y, Z you know what I mean, can you see the logic in that?"

"I think that there is lack of management or bad organization and rota. "

"I feel that the image here is deceptive you know the quality, they have beautiful carpets, they have beautiful rooms, everything is spotless now I would have to say that. They got new uniforms after twelve months; they got a second bus you know in a couple of months. There is a beautiful image here unfortunately the quality of service isn't being maintained and there is no shortage of money you know for the things that are needed. The facilities are there and the service isn't being delivered."

"I find there is nothing to be offered here for me on a Friday. It is degrading to come in and sit here from half past ten until two or three o'clock. I know it is lovely to have your lunch handed up but it doesn't justify. The lunch doesn't justify that number of hours and there just aren't the personnel here."

"A low standard in the extras that are currently being provided that is the way I would put it a very low standard in the services being provided, they leave a lot to be desired... and I am not speaking for myself I am speaking for a lot of people."

The Day Care service appears to meet carer's needs but not all of patients needs, though both parties indicated that there was a gap in the on-site provision of medical input to Day Care.

"But there could be medical input in that if they had something minor it meant that they had to leave the Day Care, go back to their GP and maybe get a very small thing fixed up whereas if they had connections still with some of the hospice doctors and just popped down for 10 minutes and say "look you need X, Y, Z done and here's your prescription."

"-----would ring me and she would make contact with his doctor directly that kind of thing. Now I found that such a relief because I would be the one normally ringing the doctor, ringing the neurologist, ringing the chemist, ringing the doctor, trying to do all these and trying to earn a few bob at work so when someone rang me and said "Well Anne he isn't well at the moment but I have made contact with the doctor and the doctor is saying whatever OK I'm just letting you know would that be alright and so on" and I was just saying thanks be to God someone will do something. That was great."

Hospice Home Care

The Home Care Nurses were widely perceived to provide a valuable service in co-ordinating the provision of equipment and facilities for the home to promote independence and self-sufficiency. One participant described the service as a "sterling service".

"The girl that came, -----was her name and she was fantastic because-----from a psychological and emotional point of view was able to relate to her completely and they just clicked and so I think in a way though she was nursing he just felt he was able to unload to her and I felt she was great. She would ring me and say "will I call and how are you doing"? Even just for someone to ring and say, "how are you

doing” I felt I used to get upset at the thought that at least someone was concerned to know how you were getting on. I sometimes get upset now myself even thinking about that period.”

“She (the home care nurse) put in a lot more time than she should have especially at night time. She was on the phone all the time any time I wanted any advice or anything.”

“The doctor asked them to be in touch with her and that was Monday I think. Tuesday then I rang myself and asked to speak to one of the nurses and that was I think about 11.00 in the morning and 11.20 or some time like that the nurses was out in the house and they just spent time with----- discussing everything with her, her pain now they were talking and straight away it was such a relief that was the first time that she got relief...”

“If I need to change my tablets----- would say are you taking too much of this or that...----- she’s brilliant.”

The role of the General Practitioner in home care was also widely perceived to be a valuable one by patients and relatives alike. However, some participants felt GPs were inadequately equipped to deal with palliative care issues.

“Our GP is a lovely man but he hadn’t a clue about what was going on. Not a clue. He used to depend on me he would say what do you think? - Even on the medication and all around the epilepsy. He depended on me completely and to give him my opinion as to what we felt we might do next.”

“The GP only paid one visit in three months.”

In addition to the direct role played by the home care nurses in care and treatment, their central role in the co-ordination of care by other services was also valued.

“----- (The home care nurse) she got me a special soft mattress and a seat as well.”

“She (the home care nurse) said she couldn’t discuss me because she wasn’t supposed to be with me but she said that she felt that if I needed something drastically or I was in desperate need she said she knows the doctors well enough to go quietly and say what I need and that is a great service.”

“Once the home care nurse was involved at least you could bounce things off her, she might not know the answers either but... but sometimes she would go back to the doctor in Milford and say what do you think.”

The needs for continuity of care by the same home care nurse and the need for “out of hours” cover was also expressed.

“There were a few panic stations. The first night she was released from Milford she got a seizure.... had I access to the home care nurse that time maybe she wouldn’t have had to go back in.”

“The local nurse came every day and gave her a little wash she was very good. I found at weekends then they would change----- couldn't come all the time she was on a weeks holidays as well so there was different nurses coming but there was nothing wrong with them though. I found that----- seemed to know the patients better, so the continuity would be better if there was a regular person.”

The views of the Specialists Service Providers

Specialist service providers from sixteen different disciplines were invited to three focus group sessions, held in Milford Care Centre, during April 2002.

Representatives from fifteen of the sixteen attended. Each session lasted one and a half hours to two hours. Based on a review of the literature and preliminary discussions with service providers during site visits, a topic guide for focus group sessions was drafted.

This topic guide was included in the letter of invitation to all participants and included the following topics:

- Satisfaction with services in general
- Unmet needs
- Co-ordination of services
- Communication
- Future development of the service.

Education

While all health care professionals were said to receive an introductory education in palliative care principles and practice, emphasis was placed on the need to integrate specialist palliative care throughout health care service provision. In order to achieve integration, specialist training and experience in palliative care was emphasized and it was considered that, at minimum, the lead person in each multi-professional group providing palliative care should be a trained and acknowledged specialist in palliative care. The need for continuing education for staff working in specialist palliative care and the need for study leave to be reflected in staffing levels was also emphasized.

“That is actually one of the things we discussed yesterday – unmet needs – lack of update - lack of study days, lack of facilities – we are not talking about going off to Timbuktu, we are talking about in-house plus it is all fine running these courses but give us the facilities to be able to attend these. ”

In many disciplines providing specialist palliative care, only one, sometimes part-time, person was employed, as they were not replaced during training/study leave, there was a gap in service provision.

It was suggested that the specialist staff should become part of bigger international, or national organization but be supported with adequate funding.

“Maybe the specialist care unit should have a membership of an organization as a unit so we can access information from them.”

While the library facilities at Milford Care Centre are currently being upgraded to incorporate Internet access there was an unanimous view that

“ There is no ongoing development for the people in the palliative care specialist unit – unless you go off and do a course.”

A suggestion was made by a number of participants that decentralizing courses relevant to specialist palliative care provision would be very beneficial.

“Decentralising - I find that a lot of professional training courses are up in Dublin so it is not a matter of just going, it is also a hassle travelling etc.”

While the Education Department in Milford Care Centre run a week ‘s palliative care course, targeted at health professionals working in the area of palliative care within the M.W.H.B. region, many of these participants took part during their own time and at their own expense. It was also suggested that this course could be decentralized to North Tipperary and Clare on a regular basis, thus increasing the profile of palliative care, supporting the staff who work in satellite areas and meeting the education needs of those who find it difficult to attend another venue.

A strong view emerged among the nursing participants of the group sessions where they would like to see the Higher Diploma in Palliative care for nurses developed in the University of Limerick and also the development of the advanced nurse practitioner with nurses trained to MSC level.

“We haven’t an advance practitioner. Someone needs to be trained up to MSC level for that. We have the clinical nurse specialist outside in the community, but within the hospice setting clinical nurse specialist is not – the nurse in the hospice unit is not seen as the clinical nurse specialist. They are seen as a nurse providing care within a specialist unit. It is different outside the community. There are specialists in the community, whereas they are not considered within the actual unit itself as specialist because everybody is doing the same thing.”

Some thought that video conferences would be of benefit in staff education.

“We have conference facilities. We should set that up here. Video conferences.”

Most agreed that undergraduate palliative care exposure would benefit GPs and allied professionals involved in palliative care while affiliation to an academic institution would benefit level three palliative care professionals.

“It would not be any harm at all if undergraduates had some experience, knowledge of what palliative medicine was about. There is this perception out there that you know it is the end and it isn’t worth doing perhaps, you know.”

“They need to be empowered by education in I suppose at undergraduate or post graduate level. That has to be emphasised.”

Several participants stressed the view that *“education and research isn’t a luxury, it is a necessity”*.

The group agreed the way forward for education in palliative care by teaching, communicating, and networking :

“To disseminate our knowledge so that we practically become redundant.” It was also recommended that some member of staff be sent for training in providing a lymphoedema service.

Access and Equity

The hub of specialist palliative care activity in the M.W.H.B. is Milford Care Centre, where there is a purpose built 30-bed unit staffed by a multidisciplinary palliative care team. At the time of this study only 20 of the 30 beds in the specialist unit were operational. Much discussion centred on how to make that unit fully operational. One suggestion was that five beds be used as *“an emergency step down facility”*. The absence of an admissions policy for the specialist inpatient unit was discussed, the absence of which was felt mainly to effect non-cancer patients and those requiring admission for respite or on *“social grounds”*.

The medical team accepted referrals from GP’s, the acute hospital sector and hospitals outside the Mid-West region. (e.g. St. Luke’s Hospital, Dublin) with a minimal waiting period for admission, varying from days to one week. It was stressed that patients needing respite care, or those who didn’t need a huge amount of medical intervention were not seen as a priority admission.

“Currently there is very much a medicalisation dimension to our service.”

” Favoured clientele being those with malignant conditions.”

Participants felt that adequate facilities were in place at Milford Care Centre to meet, what were now, the unmet need of these patients and that though not all patients would require admission - *“Everyone is going to die not everyone will need a specialist palliative care input”* - an admissions policy should be finalised as a matter of urgency.

Specialist Palliative Care Services in Acute Hospitals

Access to specialist palliative care in the acute hospitals is by medical referral from hospital consultant to palliative medicine consultant or hospital consultant to clinical nurse specialist in palliative care. Lone member teams with no on-site palliative consultant input work in Ennis, Nenagh and St. John’s Hospitals. In the Mid-Western Regional Hospital there are three sessions per week by the Consultant plus a registrar in Palliative Medicine with additional visits by the Consultant at night and at the week-ends as requested.

Paramedical services are accessed through the general hospital services.

Inequity in service provision is evident in the other acute hospitals with the specialists palliative care service being provided by a nurse again between Monday and Friday with no locum cover when she was off duty thus leaving a huge gap in the service.

While this service was unanimously viewed as a valuable resource, it was recommended that these services be developed with input by a Palliative Medicine Consultant and serviced by a full palliative care team. As these nurses worked in isolation incorporating many different roles into their daily discipline, the palliative care service became more fragmented. Service providers felt that because 66% of all Irish deaths still take place in hospitals these services need to be developed.

A suggestion was made for the development of a Palliative Care Outpatients where many patients could be delivered holistic care from the various members of the palliative care team on the same day. A recommendation was made that this service be run at the same time or on the same day as the oncology outpatients for patient convenience.

While the number of patients to be seen in these outpatient clinics may be small, clinics would be “*people intensive*” with an emphasis on “*quality rather than quantity*”.

The Support Bed Units

The director of nursing for each hospital, who accepts admissions from GPs, acute hospitals, and specialist palliative care teams etc., controls access to palliative care beds in community hospitals – “support beds”. The minimum wait for admission was stated to vary from “that day” service to days waiting. Some concerns were voiced in the view of our aging population that these units may not be adequate to meet service demand in years to come.

These units were seen as an invaluable service to rural areas in the Mid-West where patients may receive palliative care in their own community.

The need for such a unit in West Limerick was highlighted with support for the establishment of a palliative care unit in St. Ita’s Hospital in Newcastle West.

The need for specialist medical input into these units was also seen as a service for development.

“– But if you wanted somebody to get in to be assessed because of a specific symptom and sometimes even though it may sound awful – you are trying to get somebody in – even into the local beds because you want the patient to go away from the G.P. and to try to symptom manage them better. That is fine if you can get them to come in here, (Milford Care Centre) but if someone is not open or willing to come in to Milford then you are talking of them going in locally and it may be their own G.P looking after them again, so you have solved nothing, bar moving from their own home. ”

Day Care Services

Palliative Day Care services currently exist in Milford Care Centre only with provision of service on a Thursday and Friday only for patients living within a fifteen-mile radius.

This service is still in its infancy with client numbers not reaching capacity and no waiting list for it's access. Referral is through the GP or palliative medicine consultant. A wide range of services is offered to the patients including alternative therapies, physiotherapy and occupational therapy. The provision of the latter two are sub optimal due to staffing restraints. A transport service is offered to and from the Day Centre.

Medical input is provided in "*emergency*" situations only i.e. "*life threatening*". It was suggested that the ideal would be for the in-house doctors to service the Day Care Centre on an "*as needs basis*". It was agreed this would improve the service for the patient where they wouldn't have to leave the Day Centre and go back to their GP.

It would also help build a stronger relationship of trust and reduce the fear patients may have of being admitted to the inpatient unit at some stage in their illness.

The need for development of Day Care palliative services in Clare and North Tipperary was highlighted during discussion at each of the focus group meetings.

Home Care Services

The Home Care Team, composed of clinical nurse specialists in palliative care and a specialist registrar based in Milford Care Centre with satellite offices in Nenagh, Thurles, Ennis and Newcastle West, providing a nursing service to patients in their own home and supporting the nursing service in the support bed units throughout the Mid-West region. This service operates Monday to Friday 9.00a.m. to 5.30p.m. with "*essential calls only*", provided at the weekend by two nurses for the whole region. A telephone advice service to the inpatient unit is offered out of hours.

Access to the service is through medical referral or through the nurse specialists in the acute hospitals. There is little or no delay in receiving the service.

Gaps in the service were identified where the care may be labour intensive and the workload may be shared with the PHN. A need for care assistants in the home in these situations was seen as a possible solution.

The need for 24 hour cover in order to provide an inequitable service was discussed. To achieve this more personnel are needed. The development of GP cooperatives is likely to impact even further on this vital service.

The provision of ancillary services and equipment to patients at home is also constrained due to poor staffing levels. Positive comments were made regarding the invaluable contribution that the voluntary agencies make, both financially and in providing other forms of support for the service.

Many of the home care participants stressed the need for continuing education to keep abreast of the developments in palliative care. In order to achieve this, cover for their leave would need to be provided so as not to diminish service provision.

A view emerged at all three sessions that there was a need for a palliative care co-ordinator in the Mid-West to ensure a seamless service. Closer collaboration between the various service providers involved in home care was suggested in order to minimise the risk of disruption and inconvenience to the family or the patient with successive uncoordinated professional visits.

Collaboration between hospital and community services and efficiency in relaying information to the home care team by hospital services is essential for continuity of care. It was suggested that the hospital palliative care nurse specialists attended the weekly home care meetings to improve on this issue. It emerged that basic structures need to be put in place to allow for ease of access to communication to all specialist service providers, such as fax machines, e-mail access and IT equipment in each discipline providing a specialist service within the Mid-West region (i.e. all home care satellite offices, acute hospital nurses, support bed units etc).

Chapter Seven

Quantitative Research Results

These results refer to the postal questionnaire surveys carried out in the course of the study. Questionnaires were sent to the following groups; General Practitioners, Public Health Nurses, Specialist Service Providers, Nurse specialists with a palliative care patient caseload, Hospital Consultants with a palliative care patient caseload and Directors of nursing in Community Hospitals who offer a palliative care service. The questionnaires sought to identify palliative care activity in each setting, determine satisfaction with current specialist palliative care services, highlight areas of unmet need and elicit priority areas for future service development.

The response rate was as follows:

- | | |
|--------------------------------|------|
| • GPs | 50% |
| • PHNs | 67% |
| • Specialist Service Providers | 60% |
| • Nurse Specialists | 88% |
| • Hospital Consultants | 57% |
| • Community Hospitals | 100% |

Survey of Community Hospitals

Seven community hospitals were surveyed (response rate 100%). These hospitals ranged in size from 31 beds to 103 beds, the average hospital having 37 beds. All but one hospital had two designated palliative care beds. The largest hospital had a seven-bed palliative care unit. Two thirds of the respondents stated that they could also access other beds for palliative care patients within their hospital when the need arose. Palliative care patients were admitted for either terminal (43%) or respite (29%) care. Community hospitals accepted patients from a variety of sources as shown in Table 7.1.

Table 7.1: Percentage of community hospitals accepting patients from various sources

Source: Milford Care Centre

Accepted Source of Referral	% Of Community Hospitals
Specialist Palliative Care Services	100%
GPs	86%
Acute Hospitals	71%
Discharge Liaison Nurses	57%
Public Health Nurses	43%

One hundred percent of respondents stated that they received support from the home care nurse in their area but none received direct consultant input. All hospitals had a complement of palliative care nurses ranging from one to nine nurses with an average of two palliative care nurses per hospital and at least 20% of all nurses had both training and an excess of one year's experience in palliative care in every hospital.

As can be seen from Table 7.2 satisfaction levels varied depending on the area of service provision involved. For instance, there were high levels of satisfaction with bed allocation, overall facilities and specialist equipment while respondents were less satisfied with communication at all levels and education. There was extreme dissatisfaction with ancillary service provision for palliative care patients in this setting. When asked if they felt that overall provision of palliative care services in their hospital was adequate 16.7% of respondents said "yes" and the remaining 83.3% said "no" Figure 7.1.

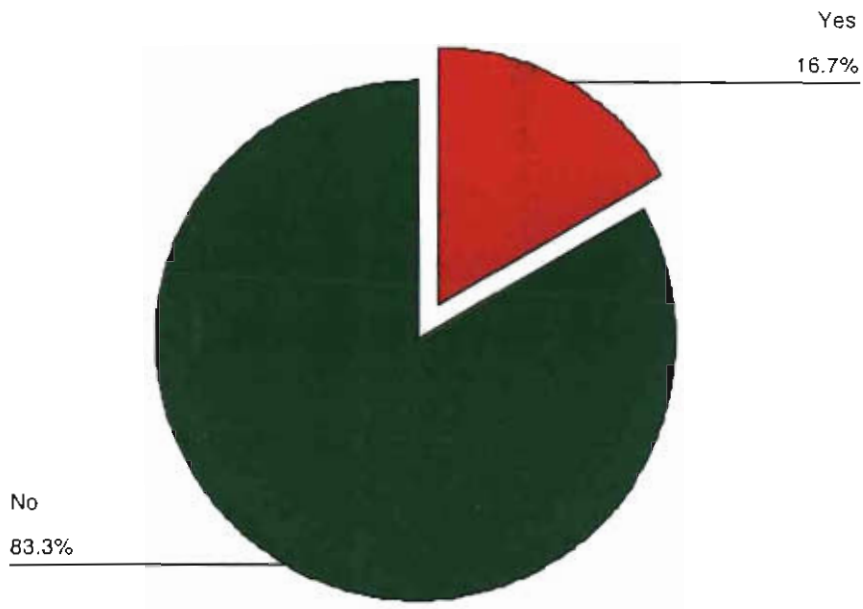


Figure 7.1: Overall adequacy of palliative care services in community hospitals

Source: Milford Care Centre

Table 7.2: Satisfaction levels among respondents to Community Hospital questionnaire

Source: Milford Care Centre

Area of service provision	Proportion satisfied/very satisfied
No. of nursing staff with expertise in palliative care	57%
No. of beds	86%
Communication with GPs	43%
Communication with specialist services	43%
Availability of assistance and advice from specialist services	43%
Availability of assistance and advice from GPs	43%
Education and training in palliative care	29%
Communication with voluntary agencies	29%
Overall facilities	71%
Specialist equipment	100%
Ancillary services	0%

Areas of unmet need specified by Directors of nursing in community hospitals as comments in response to the questionnaire are listed below.

- Paramedical services in the community (n=12)
- Complementary therapy (n=4)
- Increased nursing staff (n=3)
- Palliative Care Consultant input (n=2)
- Education (n=1)
- Facilities for relatives (n=1)

Survey of General Practitioners

One hundred and seventy five GP questionnaires were posted to GPs practising in the MWHB area as identified by the primary care unit of the MWHB. Non-responders were contacted by telephone yielding a final response rate of 50%. Figure 7.2 illustrates where responses came from within the Board area.

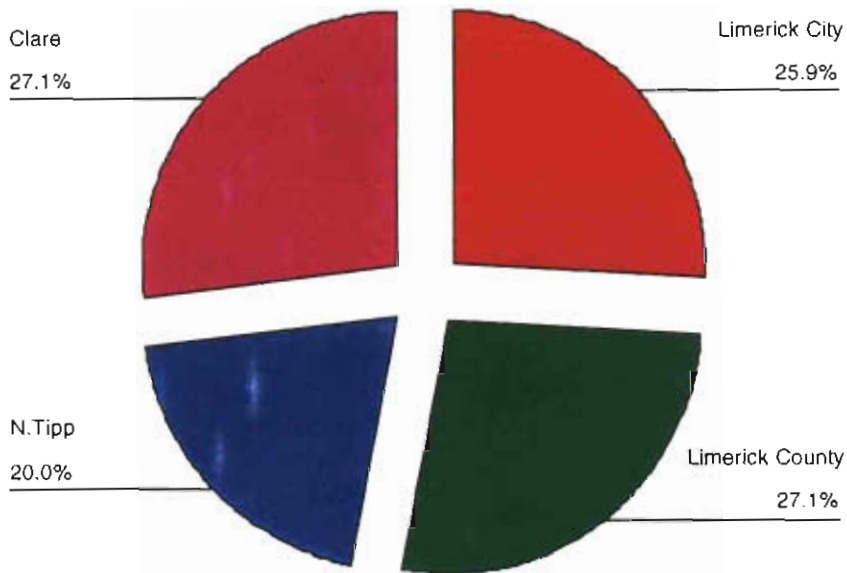


Figure 7.2: Geographical breakdown of respondents to GP questionnaire

Source: Milford Care Centre

Respondents had been qualified anything from four to 29 years with the average respondent qualified over 20 years. Fifty three percent had completed a GP vocational training programme while 47% had not. The majority (54%) operated single-handed practices with 30% working in partnership with one other doctor. Over half the respondents were from an urban or mixed practice as shown in Figure 7.3.

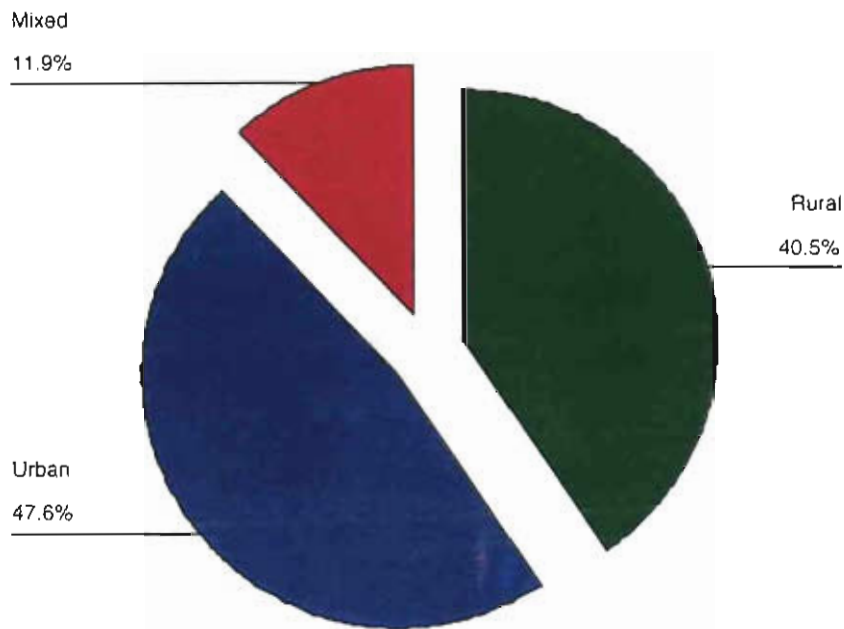


Figure 7.3: Practice type, rural, urban or mixed for respondents to GP questionnaire

Source: Milford Care Centre

One quarter of respondents had a commitment to a support bed unit in a community hospital while 67% said that they had no training or experience in palliative care. When in need of advice GPs most commonly asked the home care team, phoned the specialist inpatient unit or contacted the Consultant in palliative medicine.

Table 7.3: Common sources of palliative care advice for GPs

Source: Milford Care Centre

Source of advice	Proportion of GPs
Home Care Team	83.5%
Specialist Inpatient Unit	32.9%
Consultant in Palliative Medicine	29.4%
Designated/support bed unit in a community hospital	14.1%
CNS in Palliative Care in an acute hospital	12.9%
Day-Care	5.9%

When asked if they encountered barriers in the following areas in managing patients with palliative care needs the proportion of GPs answering “yes “ is shown in Table 7.4. The commonest difficulty appears to be in relation to patients with non-malignant conditions while as with service providers in community hospitals access to ancillary services again poses difficulty.

Table 7.4 : Barriers encountered by GPs in the provision of palliative care

Source: Milford Care Centre

Barriers to service provision	Proportion of GP
Access to Palliative care services for patients with non-cancer conditions	63.5%
Access to ancillary services	54.1%
Access to beds	36.5%
Access to services out of hours	36.5%
Transport (for patients)	22.4%
Family support to patients	18.8%
Access to Aids and Appliances	12.9%
Access to Specialist advice and support	11.8%

GPs were asked how satisfied they were with a number of features of the Specialist Palliative care service as shown in Table 7.5. They rated the advice they received from palliative care nurses highly as they did communication with all areas within the service. A common source of dissatisfaction was the reimbursement they received from the health board for palliative care services provided by them.

Table 7.5: Satisfaction levels among respondents to GP questionnaire

Source: Milford Care Centre

Area of palliative care service provision	Proportion either satisfied/very satisfied with current service provision
Advice from Specialist Palliative Care Nurses	91%
Communication with Home Care Teams	88%
Communication with Inpatient Unit	75%
Communication with support bed units	57%
Communication with Acute Hospital Specialist Palliative Care service	57%
Support for PHNs	67%
Health Board Reimbursement	28%

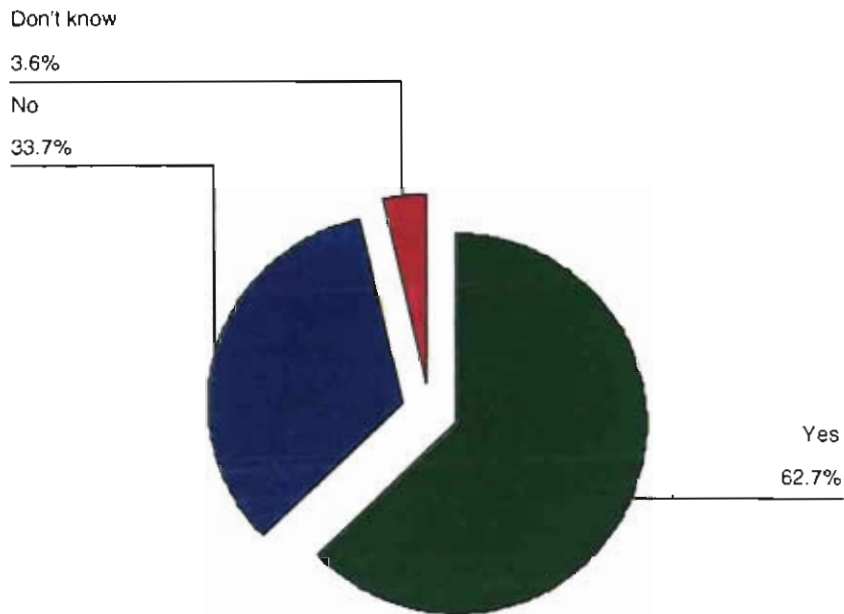


Figure 7.4: Adequacy of palliative care services for cancer patients in the MWHB as perceived by GPs

Source: Milford Care Centre

When asked if they considered the overall service available to cancer patients to be adequate the majority of GPs (63%) answered “yes” Figure 7.4, while over three quarters of the same GPs felt that the services for non-cancer were not adequate - Figure 7.5.

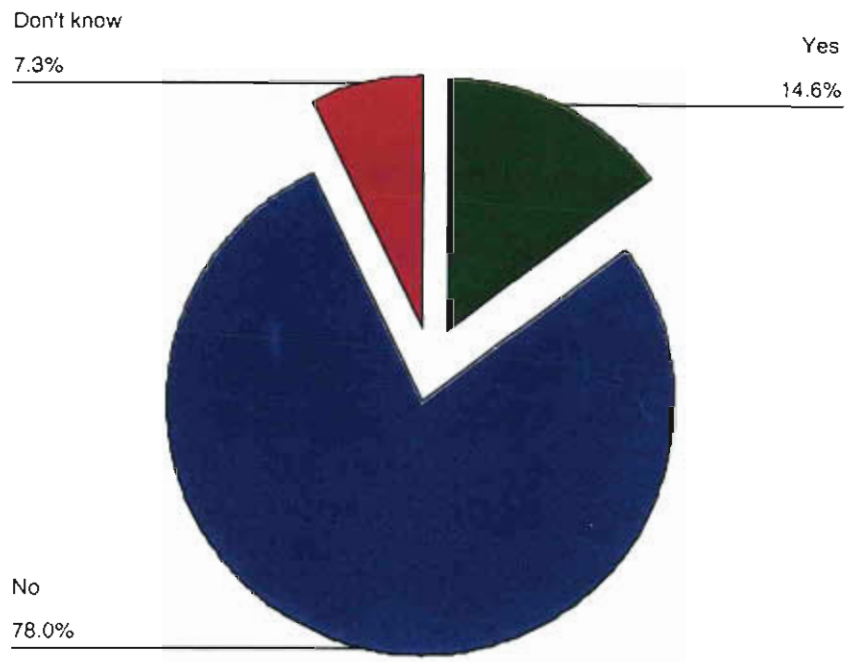


Figure 7.5: Adequacy of palliative care services for non-cancer patients in the MWHB as perceived by GPs.

Source: Milford Care Centre

An overwhelming 86% identified the need for further education in the areas illustrated in Table 7.6

Table 7.6: Percentage of GPs who identified the need for further education in each specific area of palliative care

Source: Milford Care Centre

Area requiring education	Proportion of GPs
Symptom Control	66%
Pain Control	61%
Bereavement Counselling	55%
Paediatric Palliative Care	47%
Stress Management	47%
Breaking bad news	46%

Areas of unmet need specified by GPs as comments in response to the questionnaire are listed below.

- Palliative care for non-malignant patients (n=17)
- 24-hour palliative care in the community (ex. GP “on call” cover) (n=7)
- Counselling service (n=5)
- Education (n=3)

Survey of CNS in Palliative Care

Questionnaires were distributed to the Directors of nursing in acute hospitals who were asked to identify the Clinical Nurse Specialists in their hospitals caring for patients likely to have a requirement for palliative care. The Directors of nursing identified clinical nurse specialists in Oncology, Haematology and Palliative care. Questionnaires were distributed to these nurse specialists, all located in Limerick city hospitals; the response rate was 100%.

Satisfaction was generally high with palliative care services within their area of practice though services for non-cancer patients were once more highlighted as was the need for bereavement/counselling services in the acute hospital sector, Table 7.7, but when asked if they considered the services in the Mid-West as a whole to be adequate 86% answered "no".

Table 7.7: Satisfaction levels among respondents to CNS questionnaire

Source: The acute hospitals of the MWHB region

Area of Service provision	Proportion Satisfied/Very satisfied
Overall service provision (in hospital)	86%
Communication with Specialist Service	86%
Access to Palliative Care beds	57%
Onsite palliative care services	57%
Services for non-cancer patients	43%
Counselling/bereavement services for patients	14.3%

Areas of unmet need specified by nurse specialists as comments in response to the questionnaire are listed below.

- Counselling service/psychologist support services for patients and family (n=9)
- Education (n=6)
- More palliative care staff (n=2)
- Outpatient service for palliative care (n=1)
- Involvement in management meetings/decisions re palliative care issues (n=1)
- Care of non-malignant patients (n=1)
- Improve communication in some areas of the palliative care service (n=1)

Survey of Hospital Consultants

Questionnaires were posted to 64 consultants in the MWHB with a clinical caseload relevant to the study. The response rate was 50%, and all worked in acute general hospitals. Table 7.9 below shows the specialties of those who responded.

Table 7.9: Specialties of consultants who responded to hospital consultant questionnaire

Consultant Anaesthetists	3
Consultant Psychiatricians	0
Consultant Orthopaedic Surgeons	4
Consultant Radiologists	0
Consultant Cardiologist	0
Consultant E.N.T. Surgeons	2
Consultant Haematologists	2
Consultant Medical Oncologist	1
Consultant Paediatrician	1
Consultant Physician	10
Consultant Surgeon	8
Consultant Urologist	1
Consultant Neonatologists	0
Consultant Obstetricians/Gynaecologists	1
Consultant Geriatrician	1

Hospital consultants who responded to the questionnaire were generally satisfied with services on offer to them, particularly those on site. Once again, however, the lack of services for patients with non-malignant conditions was highlighted Table 7.7. When asked about specialist palliative care services overall in the MWHB area half the respondents felt they were adequate.

Table 7.7: Satisfaction levels among respondents to hospital consultant's questionnaire

Source: The acute hospitals of the MWHB region

Area of service provision	Proportion satisfied/very satisfied
On site services	75%
Overall satisfaction	83%
Communication with Care Services	75%
Access to beds	58%
Services for non-cancer patients	17%
Counselling/bereavement services for patients	50%

The unmet needs identified by hospital consultant's comments in response to the questionnaire are shown below.

- More palliative care nursing staff (n=6)
 - Palliative care for non-cancer patients (n=4)
 - Bereavement advice/counselling for patients and relatives (n=3)
 - Additional Consultant (n=3)
 - In-patient beds in acute hospital, designated to palliative care (n=3)
 - 24-hour community nursing service palliative care (n=1)
 - Radiotherapy Rx locally (n=1)
 - Palliative care – OPD (n=1)
 - Needs for P.C. Consultant to visit Nenagh General Hospital (n=1)
 - Urgent need to restore palliative care service at N.G.H (n=1)
 - Development of paediatric palliative care (n=1)
-

Survey of PHNs

Questionnaires were circulated to PHNs and RGNs who report to PHNs in the region. A total of 61 questionnaires stratified between RGNs and PHNs and by area were circulated. The response rate was 67%, with the higher response rates coming from North Tipperary and from those operating in a rural setting. Figures 7.10, 7.11.

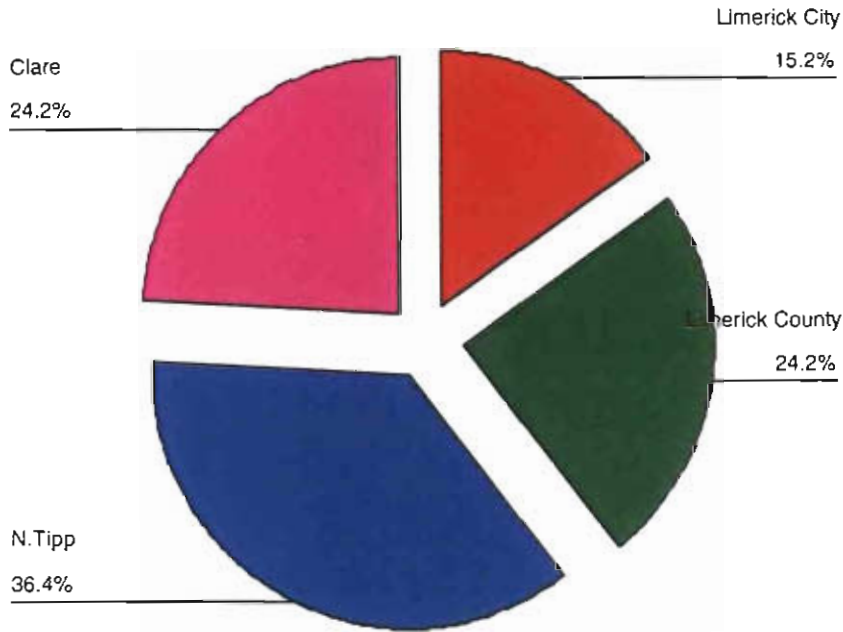


Figure 7.10: Geographical breakdown of respondents to PHN questionnaire

Source: Milford Care Centre

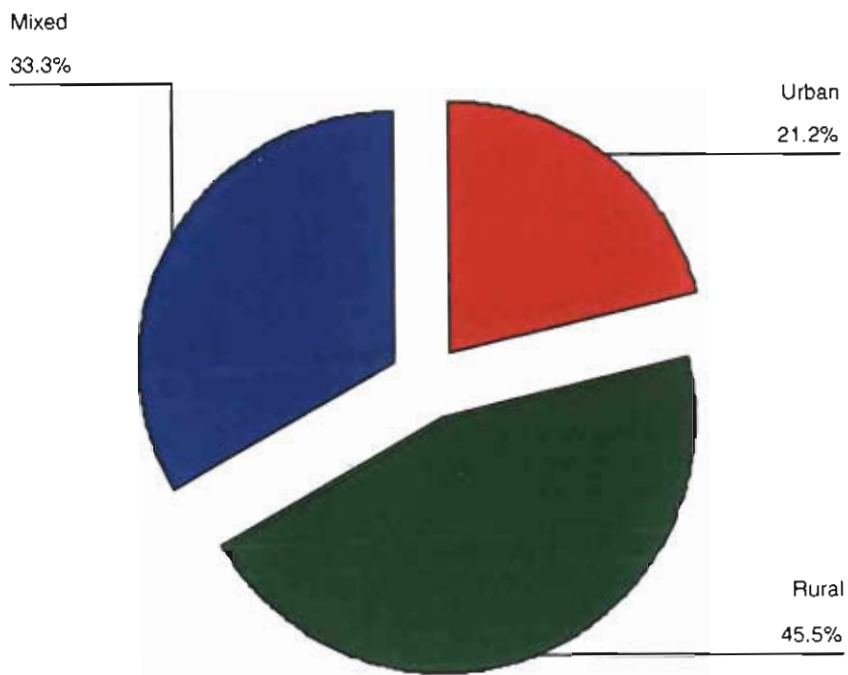


Figure 7.11: Practice type, rural, urban or mixed for respondents to PHN questionnaire

Source: Milford Care Centre

PHNs/RGNs in the community were generally satisfied with communication with palliative care services and the support/advice they received from them, Table 7.7.

*Table 7.7: Satisfaction levels among respondents to PHN questionnaire**Source: Milford Care Centre*

Area of service provision	Proportion satisfied/very satisfied
Communication with Home Care Service	85%
Communication with Milford Hospice	67%
Communication with Acute Hospital Service	67%
Communication with GPs	46%
Assistance/advice	85%
Overall adequacy of local services	67%
Ancillary services	30%
Availability of equipment	55%
Night Nurse Services	61%

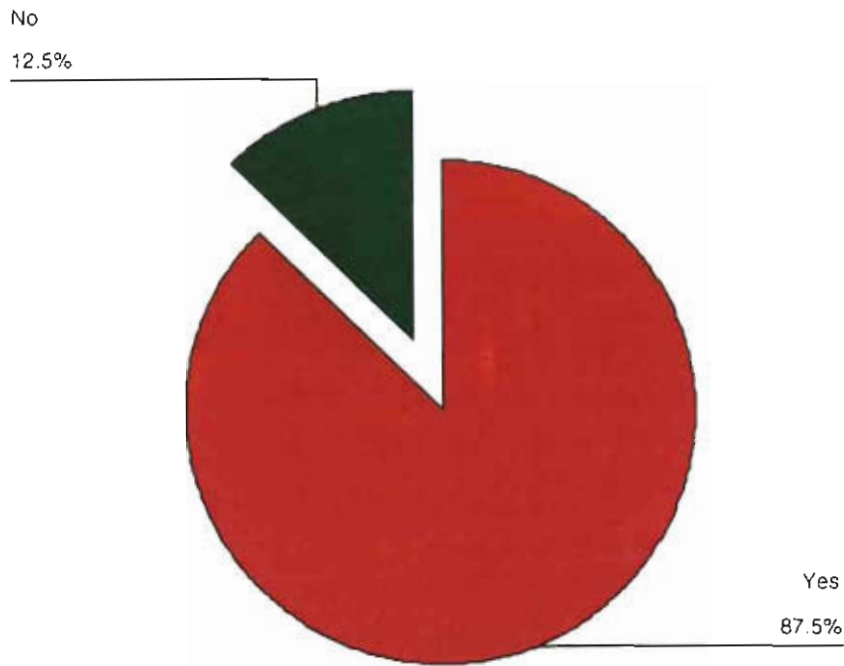


Figure 7.12: Proportion of PHNs/RGNs who identified a need for further education

Source: Milford Care Centre

Most PHNs/RGNs felt they needed further education in the area of palliative care (87.5%), Figure 7.12 the proportion requiring education in each area is shown in Table 7.8.

Table 7.8: Proportion of PHNs/RGNs requiring further education in various aspects of palliative care

Source: Milford Care Centre

Area requiring education	Proportion of PHNs /RGNs
Symptom Control	70%
Pain Control	76%
Bereavement Counselling	58%
Paediatric Palliative Care	46%
Stress Management	61%

Areas of unmet need specified by PHNs/RGNs as comments in response to survey questionnaires are listed below:

- **Development of discharge planning and support in place prior to patient being discharged to the community (n=12)**
- Sharing workload between PHN and Home Care Team (n=12)
- The need for 24-hour palliative care nursing service in the community (n=8)
- Equipment (n=7)
- Improvement for liaison/communication between hospital, hospice and community services (n=7)
- Need to develop ancillary services for palliative care in the community (n=7)
- Availability of more palliative care beds in the community (n=5)
- More support needed for carer (n=4)
- Need for community care assistants (n=4)
- Education for PHNs re palliative care issues (n=3)
- Paediatric palliative care for community needs to be developed (n=2)
- PHN referral to home care (n=2)
- Access to alternative therapies in the community (n=1)

Survey of Specialist Service Providers

Sixty percent of specialist service providers circulated with a questionnaire responded. Occupations of respondents are shown in Table 7.13.

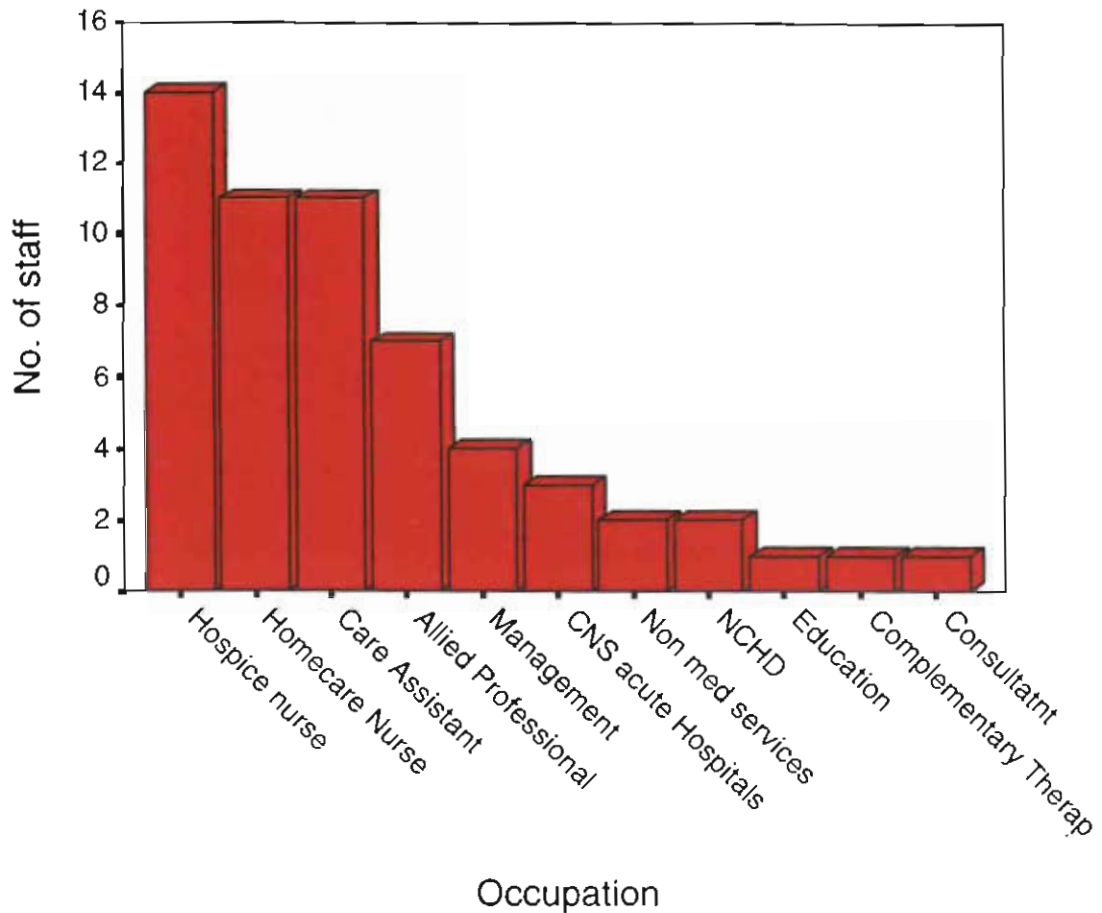


Figure 7.13: Occupation of respondents to the questionnaire for specialist service providers

Source: Milford Care Centre

Though satisfaction levels were high (Table 7.9) among respondents to the specialist services questionnaire only 10% of respondents when asked if they thought overall palliative care service provision in the MWHB area answered “yes”.

Table 7.9: Satisfaction levels among respondents to Specialist Service Provider's questionnaire

Source: Milford Care Centre

Area of service provision	Proportion satisfied/very satisfied
Satisfaction with staffing	68%
Access to beds for cancer patients	63%
Access to beds for non-cancer patients	32%
Access to respite beds	30%
Communication with GPs	32%
Stage at which patients are referred	35%
Education and training	58%
General job satisfaction and stress management	51%
Professional assistance & advice	81%
Communication with voluntary agencies	37%
Equipment	47%
Ancillary services	19%

Specialist service providers also made specific comments about unmet needs in the areas detailed in Table 7.10.

Table 7.10: *Unmet needs as identified by specialist providers in response to questionnaires*

Source: *Milford Care Centre*

Unmet needs	Number
Need for development of community and acute hospital ancillary services especially O.T. and Physiotherapy.	24
Improve communication between all members of the palliative care team	12
Development of education re palliative care issues to all S.S.P.	14
Maximising the use of existing beds for palliative care	10
Additional palliative medicine consultant	6
Broaden the services to include non-malignant diseased patients	6
Appointment of CNS posts in the hospice unit	3
Equipment (easy and quick access to it)	4
Improve staff support and facilities	6
Units set up to meet the needs of children and teenagers	6
24-hour palliative care nursing in the patients' home	9
Palliative day treatments for all areas in the MWHB	6
Radiotherapy unit for MWHB region	3
Joint OPD clinics with oncology/surgery/radiotherapy	3
Need for a lymphoedema service	5
Development and greater use of complementary therapies	2
Recognition of the role and value of volunteers	1
The development of research projects	1

Chapter Eight

DISCUSSION

The population of Ireland and indeed of the Mid-West is ageing and with this changing demographic profile comes an increasing demand for palliative care services for older people.

This is coupled with the acknowledged need for specialists in palliative care to become involved in the management of more non-malignant illness, many of which carry a prognosis comparable with progressive malignancy. For instance the Framingham Heart Study found that once heart failure had developed 25% of men and 38% of women were alive after five years. Half of all heart failure patients die within four years and of those with severe heart failure half die within the first year. While the determination of which patients with non-malignant disease require a palliative input and when precisely this is appropriate, presents a challenge to physicians, this does not diminish the need for specialist palliative care of these patients.

A model of palliative care, which was originally developed for younger patients with cancer, will now have to adapt to many older patients and to a wider range of diagnoses.

With an emphasis on “Patient Centeredness, Equity, Quality and Accountability “ this model will need to be sufficiently flexible to respond to variable patient and family needs.

Epidemiological research suggests that during the last year of their lives people will need palliative care in one or more of the following settings:

- Their family home
- Nursing home or residential home
- Acute or other hospitals, hospice
- Specialist palliative care unit
- Other institutional settings, e.g., Residential Centres for persons with a learning disability.

Among the factors influencing where care takes place are how far patients are disabled by their illness, the rate of progression of their disease, the extent to which they may be cared for by family and friends and the exercise of their personal choice over their care.

At a time in people’s lives when so few opportunities for choice remain for them the provision of palliative care should be patient focused with patient preference at its very core. When this preference is to die in the comfort of familiar surroundings, as shown by trends in the Mid–West and supported in the literature, then palliative care should be delivered to the patients home or as close to it as possible. This service should be of the highest quality independent of the patient’s diagnosis, age gender or domicile.

Because so many patients are admitted to hospital in the last year of life palliative care services in acute hospitals are also important. Oncology services are expanding and this has implications for palliative care not only within acute hospitals but all aspects of the service. Unique alliances exist within acute hospitals between specialties, such as paediatrics, neurology and infectious disease, which are involved in the care of patients with palliative care needs. Finally patients attend acute hospitals regularly and in earlier stages of their disease and palliative care services need to capitalise on this.

A number of patients present difficulty in the management of complex symptoms. This necessitates admission to a highly specialised unit. Such units are best equipped to meet patients' medical, psychological and spiritual needs in times of difficulty, independently of but in close proximity to the acute hospital. An increased demand for this service is anticipated with the broadening of categories of admission, development of services such as lymphoedema services, the need for respite admissions and consultant input into homecare.

As documented in Chapter Five the number of discharges from the Specialist Inpatient Unit at Milford have increased, the workload of the staff in the unit increases with the increase in the number of discharges.

To provide specialist palliative care to all dying patients would be both impractical and unnecessary. This is not to say, however, that most patients don't require a palliative approach in the provision of their terminal care. This presents yet another challenge to Specialist Palliative care providers to disseminate the palliative care message leading the development of continuing education and research programmes and providing specialist advice and support to primary secondary and tertiary care.

Palliative care crosses the spectrum of hospital, community, primary care and long stay services so education of all disciplines involved is vital along with effective communication and clear protocols. For this reason clarity in relation to referral criteria to the service is important.

Chapter Nine

CONCLUSIONS AND RECOMMENDATIONS

CONCLUSIONS

The partnership of the statutory and voluntary sector, namely Milford Care Centre as the Specialist Palliative Care centre for the region, Cahercalla Community Hospital and the North Tipperary Hospice Foundation and the MWHB, has achieved a certain level of success in the provision of specialist palliative care services in the Mid-West.

The care provided by staff from all sectors is of a high standard, as evidenced by the views of the patients and relatives interviewed in this study. However, gaps still exist and there is scope for improvement, a fact supported by the views of service providers during focus group sessions and in response to study questionnaires. In short the need is for patients to have time from experienced practitioners in palliative care in a variety of settings.

The current provision of specialist palliative care does not address all the needs identified by this study and the gaps in all areas of service provision have been recognised. The key issues that have emerged from the needs assessment process are described below grouped under relevant headings:

Community Services

Though the Consultant in Palliative Medicine has a regional remit, primary responsibility for patients in the community remains with the patients own GP. This compromises patient care at home care particularly in the limited, but significant, number of cases where the GP is not familiar with, or supportive of the principles of palliative care or where there is a lack of understanding of the role of the specialist palliative care nurse. In addition the introduction of GP co-operatives may affect the access of palliative care patients to 24 hour community support.

Many patients particularly those resident in more remote regions who require inpatient management of symptoms opt for admission to local support bed units rather than the specialist unit in Milford which is at a distance from them. These units often lack the expertise in complex symptom management necessary to alleviate the suffering of such patients, but patients choose familiar surroundings and close proximity to relatives and friends.

Within support bed units patients suffering from non-malignant disease are underrepresented, some units accepting cancer patients only.

Home care services operate seven days a week from nine to five-thirty but with reduced cover at weekends when only essential calls are made.

General nursing care and additional palliative care of the palliative care patient is provided by PHN's. The service provided by PHN's is in addition to their already heavy workload and is often not acknowledged and under supported.

Night nurse services are provided by the ICS. Nurses must be accessed locally usually by a member of the specialist palliative care service, and be on the "live nursing register". The ICS funds this service up to a maximum of five nights per patient. In North Tipperary the North Tipperary Hospice Foundation provides additional funding for night nursing while everywhere else alternative arrangements have to be made.

There is no specialist community physiotherapy or occupational therapy service. Palliative care patients requiring these services access them through community care and though treated as priority cases, which guarantees assessment within two weeks, many patients either die or are admitted to hospital/hospice while waiting. Within acute hospitals palliative care ancillary services are available only at the MWRH via the Cancer Services. (Eg Social work and dietetics)

Except for North Tipperary where the North Tipperary Hospice Foundation operates a service, problems similar to those encountered with ancillary services are experienced in obtaining specialist equipment.

While there is a pharmacist based in Milford Care Centre whom liaises with pharmacists in the community such a service does not exist in other settings. This poses difficulty for staff and patients alike especially at times such as discharge home from hospital (especially those outside the MWHB etc).

There is differential access to Day Care services between patients living in the greater Limerick City area and those living beyond a fifteen-mile radius of Milford Care Centre, where the only palliative Day Care Centre in the Mid-West is located.

Day Care is available on Thursdays and Fridays when there is limited physiotherapy and occupational therapy service and access to the medical team in urgent situations. Day Care appears to meet the needs of carers very well but not always the range of patient needs.

Specialist Inpatient Unit

Demographic trends and the referral of patients suffering from conditions other than cancer for palliative care, indicate a need for further in-patient beds to be available. A clear policy stating the criteria for admission to the specialist inpatient unit is complete and appended. The majority of patients admitted to the specialist inpatient unit have cancer.

Intermediate level care is not available in the greater Limerick area, the choice for patients being between highly specialised service operated in the unit and homecare.

Acute Hospital Services

There is differential access between the MWRH and other acute hospitals in the region to a consultant led service. All wish to have access to a consultant led service.

There is a perception of professional isolation for the nurse specialist, particularly in Nenagh, Ennis and St. John's hospitals. Though provision has been made for clerical support in this setting the professional isolation experienced there is a source of stress to service providers themselves and is unsustainable in terms of nursing staff retention.

Palliative care patients from Milford Care Centre and from the community have similar access to radiology services, as do all other outpatients. This is inappropriate as is the length of time spent waiting for reports when investigations have taken place. (Particularly in emergencies such as Spinal Cord Compression, Superior Vena Cava Obstruction etc.)

Radiotherapy treatment services are located in Dublin and Cork with a weekly clinic in MWRH. A review of radiotherapy services nationwide is underway and we await its recommendations regarding the location of radiotherapy services elsewhere in Ireland. Meanwhile, patients from the MWHB area have the least access to radiotherapy services in Ireland and it is presumed that this includes palliative treatment. This report supports the MWHB submission to the National Committee on Radiotherapy recommending a radiotherapy service for palliative care patients in the Mid-West.

Education Training and Research

Nursing staff have their training in palliative care funded by the relevant nursing education budget. However there appears to be a perception that this is not available or difficult to access. A spectrum of training needs were identified ranging from the general (communication) through to the specific (lymphoedema management).

In order that the principles of Palliative Care are accepted and practised by all health professionals Milford Care Centre should maintain its role as a centre for education, research and training. With this in mind there should be affiliation with an academic institution, e.g. University of Limerick with the possible aim of creating an academic unit.

RECOMMENDATIONS

A charter for palliative care for the Mid-West should be developed to clarify the principles governing service delivery for consumers and professionals. This should include principles of Equity (geographical, financial etc.) Quality, Accountability and Patient Centeredness.

A consultation process should now commence with major stakeholders to disseminate the findings of this needs assessment.

Following the consultation period a strategic plan for service development to meet the needs identified in this report, should be developed indicating priority developments and specification of exact requirements over a five and ten year period.

Coordination of Care

Because of the wide range of organisations involved in the provision of palliative care and the wide number of services, coordination is required at all levels. A coordinator for palliative care services should be appointed to liaise with patients and between organisations and systems to allow for the seamless delivery of service. While at all times respecting patient confidentiality, the possibility of shared record keeping or patient held records should be explored. Regional Palliative Care Committees have been appointed to facilitate co-ordination. Agreed protocols should be developed and disseminated to support the co-ordination of care throughout the spectrum of services.

Accessing the service is a particular issue in a rural region consideration needs to be given to a more individualised patient transport system.

Community Services

There should be increased consultant input into palliative care in the community. Medical care should be provided in partnership between the consultant led palliative care team and the patients own GPs, a model similar to that utilised in the provision of outpatient services would be appropriate. The community palliative care team should also provide a service to palliative care patients in community hospitals.

The Home care nurse service should be extended to provide full seven-day cover. A state funded night nurse service operated by Registered General Nurses (RGNs) (with additional training in palliative care but not necessarily to specialist level) should be developed. Care attendants with training in palliative care should be available to patients in the community.

The physiotherapy, occupational therapy and social work service within Milford Care Centre should be developed to meet palliative care needs outside the specialist inpatient unit. Additionally other therapies are required particularly psychological support.

An equipment store should be created and maintained either by the Health Board or by Milford Care Centre to meet the needs of palliative care patients in the community.

Local arrangements between pharmacists in specialist care units, hospitals and in the community should be formalised to ensure that patients receiving palliative care have access to all necessary medications as and when required.

Day Care should be further developed within the Milford Care Centre and in other community locations. A palliative care support bed unit be developed as a matter of urgency at St. Ita's Hospital, Newcastlewest. Additional capacity should be contracted for at Cahercalla Hospice.

Pastoral Care services should be developed in the specialist in-patient unit, acute hospitals and in the community.

Specialist Inpatient Unit

Further specialist in-patient beds are needed. All patients who need specialist palliative based on their needs and irrespective of their diagnosis should be admitted to a specialist in-patient unit. This should be monitored regularly.

Service providers should review facilities within the unit and make the necessary changes in terms of staffing and equipment to meet the needs of patients suffering from conditions other than cancer. Staffing levels in the unit should be reviewed to conform to international norms. Physiotherapy, occupational therapy and social work departments should be developed in line with the recommendations detailed for the development of community services. In addition professionals should develop subspecialties such as lymphodema management.

The development of "intermediate level" or "step down" palliative care and respite palliative care should also be considered in this setting.

Acute Hospital Services

The majority of patients receive the news about their terminal illness in a hospital setting, increased care and attention needs to be given to the mode and place where this takes place to ensure the continued dignity of the patient. The service should be planned to allow this.

The palliative care service should be developed within the four acute hospitals in the MWHB to include the possibility of out-patient services. The number of consultant sessions in the Palliative Medicine should increase and this should allow additional sessions at the MWRH and the commencement of sessions in the other three hospitals as a matter of urgency.

Additional specialist nurses should be appointed to each hospital with an end to one-person palliative care teams. Paramedical services should be provided either separately or given priority within general services in acute hospitals.

Within the radiology service palliative care patients should be given priority, investigations should be performed and reported on an urgent basis and not on an outpatient basis as they are at the moment. IT linkage with radiology and laboratory services already in existence at ward level in the Mid-Western Regional Hospital should be extended to the Palliative Care Service.

While MWHB patients are required to travel for radiotherapy treatment, the MWHB should endeavour to provide them with appropriate transport and accommodation and escort nurses to accompany patients travelling by ambulance between hospitals

Education, Training and Research

In order that the principles of Palliative Care are accepted and practised by all health professionals Milford Care Centre should maintain its role as a centre for education, research and training. Consequently, there should be on-going funding for research positions in the medical nursing and paramedical aspects of palliative care.

As we aspire to clinical excellence so too should we aspire to academic excellence in palliative care in the Mid West. With this in mind there should be affiliation with an academic institution, e.g. University of Limerick with the possible aim of creating an academic unit.

Additional resources should be allocated for the education of nursing and medical staff working outside the Centre and consideration given to holding training sessions in locations outside the Care Centre itself e.g. community and acute hospitals.

All MWHB staff in training positions, GP trainees, student nurses, SHO's in medicine and surgery, etc. should rotate for a period of training through the specialist palliative care service. (This is already the case for student nurses training in the MWRH, and medical undergraduates from University College Cork, also GP trainees attend for one half day session.)

Audit and Evaluation

Reliable, accurate, complete, up-to-date and secure information is critical to the delivery of a high quality palliative care service. Advances have been made in recent years using palliative care information systems. This needs to continue in order to evaluate services and make provision for their development.

Multidisciplinary audit of palliative care services should be supported.

APPENDIX ONE

STEERING COMMITTEE MEMBERS

Mr. James Conway	- A.C.E.O. Mid-Western Health Board
Mr. Pat Quinlan	- Chief Executive Milford Care Centre
Dr. Sinead Donnelly	- Consultant in Palliative Medicine
Ms. Catherine Hand MHRH	- Oncology Nurse Services Manager
Dr. Tessa Greally	- Specialist in Public Health Medicine
Mr. John Cullinane	- Primary Care Unit Manager

RESEARCH TEAM

Dr. Orla Healy	- SpR in Public Health Medicine
Carmel Sheehy	- CNS in Palliative Care

ADMINISTRATIVE SUPPORT

Kathleen Hackett

Geraldine Hussey

APPENDIX TWO

GUIDELINES FOR A PALLIATIVE CARE NEEDS ASSESSMENT

The three key components of a health needs assessment include:

- The gathering and interpretation of epidemiological and demographic data.
- The estimation of the views of the major stakeholders, including service providers, service users and purchasers/planners.
- The collection and collation of comparative data relating to outputs, outcomes and costs.

1. POPULATION DATA

An analysis of epidemiological and demographic data forms the first key dimension of any assessment of health need.

1.1. EPIDEMIOLOGICAL DATA

In the palliative care context, this will include estimating the incidence and prevalence of conditions such as cancer and other progressive non-malignant diseases, taking into account local and regional variations. Information sources that can be used include the National Cancer Registry, the Hospital In-Patient Enquiry (HIPE), the Public Health Information System and Central Statistics Office data. Although neither incidence nor prevalence necessarily equates with need, a knowledge of both of these rates is an essential starting point for a needs assessment to describe the burden of disease in the region.

1.2. DEMOGRAPHIC DATA

Current incidence and mortality rates for cancer and other progressive diseases can be applied to future population figures, predicted by using population projections, to estimate the expected number of cases of and deaths from a specific disease in the future. This can be useful in predicting future service needs.

2. STAKEHOLDER PERSPECTIVES

The perspectives of key stakeholders regarding present services and how they could be improved is a key component of any health needs assessment. For palliative care services the key stakeholders include service users (patients and carers), service providers and service planners. Both qualitative and quantitative techniques may be used including:

- (a) interviewing patients and their family members individually or in focus groups.
- (b) sending questionnaires to service providers or planners.

3. COMPARATIVE DATA

This part of the process is concerned with the outputs, outcomes and costs of services.

3.1. OUTPUTS

Firstly, the palliative care services that are currently provided in a health board region should be documented. For inpatients units, indicators of utilisation such as admission rates, discharge rates, bed occupancy, average length of stay, throughput, turn-over intervals and death-to-admission rates can also be described. Service utilisation figures can also be collected and collated for day care (e.g. number of patients seen per annum, average number of visits per week) and home care services (e.g. number of patients seen by service, average number of home visits per patient). Data should also be collected regarding waiting times to avail of the various services. This information can be obtained by collaborating with service providers.

3.2. OUTCOMES

For the palliative care services, outcome measures can include place of death, patient satisfaction with services and satisfaction of family members with the process of dying and with bereavement services.

3.3. COSTS

The funding of palliative care services is often provided by both statutory and non-statutory agencies. The cost of providing these services can be examined using a simple cost analysis. Sources of funding can also be examined, where this information is available.

Information regarding the cost of providing palliative care services can be obtained from the annual reports of existing palliative care services and by contacting the administrators of the various services.

REFERENCES

1. Clark D, Malson H. Key issues in palliative care needs assessment. *Progress in Palliative Care* 1995; 3:53-5.
2. Williams R, Wright J. Epidemiological issues in health needs assessment. *BMJ* 1998; 316: 1379-82.

APPENDIX THREE

QUESTIONNAIRES

- 3.1 Questionnaire for Hospital Consultant**
- 3.2 Questionnaire for G.Ps.**
- 3.3 Questionnaire for Specialist Service Providers**
- 3.4 Questionnaire for Community Hospital Matrons**
- 3.5 Questionnaire for Nurse Specialists**
- 3.6 Questionnaire for Public Health Nurses**

APPENDIX FOUR

4.1 INTERVIEW TOPIC GUIDE USED FOR SPECIALIST SERVICE PROVIDERS

- ◆ **Communication.**
- ◆ **Satisfaction with services in general.**
- ◆ **Unmet needs.**
- ◆ **Co-ordination of services.**
- ◆ **Education.**
- ◆ **The stage at which you get involved in patient management.**
- ◆ **Adequacy of present number of staff providing palliative care. Which areas could do with more staff?**
- ◆ **Identify any patient needs that are not being adequately addressed at present.**
- ◆ **The more negative aspects of current palliative care services:**
 - for patients
 - for staff (job satisfaction; morale)
- ◆ **Liaison with General Practitioners regarding patient care – satisfactory; areas for improvement.**
- ◆ **Adequacy of education and training for your job. How could it be improved?**
- ◆ **Adequacy of current provision of palliative care services for those with non-malignant disease.**
- ◆ **How should services develop in the future?**
 - Is there a need for more inpatient hospices?
 - Should day Care/home care be expanded?
 - Should there be more out-patient services?
- ◆ **Have you worked in palliative care in other countries and experienced other models of palliative care provision?**

4.2 INTERVIEW GUIDE USED WITH PATIENTS AND FAMILY MEMBERS

- ◆ General opinion of care.
- ◆ Co-ordination of care.
- ◆ Support systems (in hospice/in community).
- ◆ Satisfaction with management of problems: Physical, psychological and spiritual.
- ◆ Communication with staff (palliative care team, GP, hospital staff).
- ◆ Level of information received from staff – Satisfactory.
- ◆ Adequate number of staff?
- ◆ Comfort of surroundings (hospice).
- ◆ Any difficulties obtaining equipment etc.?
- ◆ Happy with frequency of visits (home care/day care)?
- ◆ Any delays involved in receiving services.
- ◆ Satisfaction with ancillary services received.
- ◆ Involvement of family/friends.
- ◆ Communication between family and staff.
- ◆ How would you rate your quality of life?
- ◆ Identify any stressors.
- ◆ Day Care – any problems with transportation, etc.
- ◆ Any needs that were not met?
- ◆ Suggestions on how services could be improved.

APPENDIX FIVE

PARTICIPANTS OF THE FOCUS GROUP INTERVIEWS WITH SPECIALIST PALLIATIVE CARE SERVICE PROVIDERS

- GROUP 1**
- General Manager - Milford Care Centre**
 - Pastoral Care representative - Milford Care Centre**
 - Pharmacist - Milford Care Centre**
 - Principal Social Worker - Milford Care Centre**
 - Clinical Nurse Specialist in Palliative Care - Ennis General Hospital**
 - Home Care Nurse Representative from Co. Clare**
 - Clinical Nurse Specialist in Palliative Care at MWRH**
 - Ward Sister in the In-patient Unit - Milford Care Centre**
 - Apologies from the Director of Nursing Services - Milford Care Centre**
 - Invited but did not attend – Consultant in Palliative Medicine**
- GROUP 2**
- Director of Nursing Services - Milford Care Centre**
 - Assistant Director of Nursing Services - Milford Care Centre**
 - Consultant in Palliative Medicine – Milford Care Centre**
 - Physiotherapist – Milford Care Centre**
 - Occupational Therapist - Milford Care Centre**
 - Home Care Nurse Representative – Limerick City Area**
 - Home Care Nurse Representative – County Limerick**
 - Clinical Nurse Specialist in Palliative Care – St. John’s Hospital**

**Home Care Nurse Representative - North Tipperary
North Tipperary Support Beds – Representative (Ward Sr.)**

Co. Clare Support Beds Representative (Staff Nurse)

Staff Nurse in Day Care Centre - Milford Care Centre

Registrar in Palliative Medicine - Milford Care Centre

GROUP 3

Volunteer Co-ordinator – Milford Care Centre

Music Therapist - Milford Care Centre

Education Co-ordinator - Milford Care Centre

Aromatherapist – Milford Care Centre

Representative from North Tipperary Hospice Foundation

Community Occupational Therapist – Co. Clare

Representative from Cahercalla Hospice, Ennis (Ward Sr.)

**Invited but did not attend - Fundraising Department –
Milford Care Centre**

APPENDIX SIX

SUBMISSIONS TO THE SPECIALIST PALLIATIVE CARE NEEDS ASSESSMENT IN THE MID-WESTERN HEALTH BOARD REGION

- 6.1 Submission from Dr. Sinead Donnelly – Mid-Western Health Board Palliative Medicine, Acute Hospital Sector Vision 2002 and beyond**
- 6.2 Submission from Education Department, Milford Care Centre.**
- 6.3 Board Submission on Needs Assessment in Palliative Care, June 2002 from Milford Care Centre .**
- 6.4 Submission from O.T. Department, Milford Care Centre – Bank of Equipment/Community-based Occupational Therapist.**
- 6.5 Submission from North Tipperary Hospice Foundation.**

APPENDIX SEVEN

TERMS OF REFERENCE

The Terms of Reference of the Palliative Care Steering Committee in the Mid-Western Health Board were as follows:

- 1. To undertake a Needs Assessment to define the palliative care needs within the Mid-Western Health Board catchment area.**
- 2. To identify personnel to undertake the Needs Assessment Study.**
- 3. To ensure the Needs Assessment Study would be conducted within the timeframe recommended in the National Report (i.e. 9 months from its publication).**
- 4. To agree on the methodology for the Needs Assessment in the Mid-Western Health Board.**
- 5. To monitor and review the progress of the Needs Assessment Study at regular intervals.**
- 6. To agree and finalise the final draft of the Needs Assessment Study.**
- 7. To establish a Regional Committee at the Mid-Western Health Board level to apply national policy as determined by the Department of Health and Children with particular regard to local needs and resources.**



MID-WESTERN
HEALTH BOARD

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