

Palliative Care Needs Assessment:
Laois, Offaly, Longford and Westmeath

Executive Summary



Feidhmeannacht na Seirbhíse Sláinte
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This research was designed and undertaken in 2001/2002 by the Midland Health Board as the statutory provider of health services in the counties of Laois, Offaly, Longford and Westmeath. Consequently the services referred to in this report were those provided by the Midland Health Board at the time the research was undertaken.

In January 2005 the Health Service Executive took over the statutory responsibility for the provision of services in these counties.

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EXECUTIVE SUMMARY

Introduction

This palliative care needs assessment in the Midland Health Board (MHB) was carried out in response to the Report of the National Advisory Group on Palliative Care (2001), which identified the need for such an assessment in each health board. This report made a number of recommendations for the future development of palliative care services in Ireland, including specialist and general palliative care services.

The World Health Organisation (WHO) defines palliative care as the continuing active total care of patients and their families, at a time when the medical expectation is no longer cure.

Specialist palliative care services are those services with palliative care as their core specialty and which are provided by a multi-disciplinary team, under the direction of a consultant in palliative medicine.

The template from the needs assessment for palliative care carried out in the Eastern Health Board (Eastern Health Board, 1999) was used as a basis for the present report. There are some important differences between the Eastern Health Board and the Midland Health Board that required consideration in this Board's report. The Midland Health Board is more rural, and has an older age profile than the Eastern Health Board. In addition, because there is no hospice unit in the Midland Health Board area, palliative care services have had a very strong community focus with very significant inputs from generalist as well as specialist palliative care.

The literature review shows that there are issues around;

- Specialist and/or generalist provision of palliative care services
- Communication
- Referral to and discharge from specialist palliative care
- Education and Training
- Need for more specialist and generalist support
- Palliative care services for patients with non-malignant disease

Aims

- The aim of this study is to determine the potential for improvement of the Specialist Palliative Care services in the Midland Health Board by looking at current service provision and by examining the needs for such services.

Methodology

A Regional Steering Group was convened to oversee and advise on the needs assessment process, and a research subgroup was formed to carry out the research. Ethical approval was obtained from the local ethics committee. There were three components to the needs assessment

- Comparative needs assessment (collection and collation of service utilisation data)
- Analysis of demographic and epidemiological data
- Corporate needs assessment (views of major stakeholders including service providers and service users using quantitative and qualitative methods).

Findings

Current Services and Service Utilisation Data

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Data were gathered relating to Specialist Palliative Care Services in terms of staff and facilities. The only specialist palliative care service in the Board's region is the specialist palliative care nursing service in the community. This service works in conjunction with the home care teams including GPs, public health nurses, registered general nurses and twilight nurses. Activity data from these teams was supplied by the Directors of Public Health Nursing in Longford/Westmeath, and Laois/Offaly. GPs provide palliative care services to patients in their homes, or in nursing homes and community hospitals. Data on claims by GPs to the General Medical Service Payments Board was also obtained.

Key Findings

- There are 11 palliative care beds (five of these beds are designated as palliative care beds, the other six are respite beds) provided by the Midland Health Board. The breakdown is uneven across the Board with eight in Laois/ Offaly and three in Longford/ Westmeath. One of the beds in Westmeath is part funded by the North Westmeath Hospice Agency.
- There are nine whole time equivalent (WTE) Palliative Care Nurses operating in the Midland Health Board at present. In 2001, Home Care Teams catered for 430 patients considered to require palliative care, while there were 371 deaths. The teams provided over 4,000 home visits and 1,000 hospital visits. The figures were higher in Longford/Westmeath.
- GPs in Longford also have higher numbers of GMS claims for palliative care patients. This may reflect the fact that more Patients die in the community. In Longford 69% of patients die in the community while the overall Board percentage is 36%.

Demographics and Epidemiology

According to census 2002 the population of the Midland Health Board is 225,363, an increase of 10% over the 1996 figures. The highest percentage change is seen in Westmeath which increased by 14%. According to CSO projections for Ireland 2001-2031, the number of older persons (65 and over) will increase, and the very old population, those aged 80 and over will double by 2031. The Midlands will have the oldest age profile of all health boards, and the dependency ratio for older people is predicted to be the highest in the country at 69.4.

Key Findings

- Recent statistics indicate that approximately 426 people die from cancer in the Midland Health Board each year, 117 in the under 65 age group, and 309 for the over 65 age group.
- The greatest causes of death from cancer in the Midland Health Board were lung cancer (18%), colo-rectal cancer (12%), and breast cancer (9%). This is similar to the national picture.
- Sixty percent of Midland Health Board cancer deaths occur in hospital and 30% at home. While 6% of deaths occur in nursing homes, the figure was higher in Longford at 15%.
- The commonest cancers (excluding non-melanoma skin cancers) are colo-rectal (14%), breast (14%) and lung cancer (11%). This is consistent with national figures.
- The projected numbers of cancer cases in the Midland Health Board indicate that by 2005 there will be 773 cases, 831 cases by 2010 and 903 cases by 2015. This represents a 20% increase over the next decade.
- It is estimated that there are 1418 deaths per year in the Midland Health Board due to progressive non-malignant disease and that of these, 284 patients per year would be considered in need of palliative care services. If malignant and non-malignant figures are combined, about 600 patients could be expected to benefit from palliative care in each year and this figure will increase over the next decade.

Stakeholder Perspectives: Quantitative Study

Section 1:GPs

One hundred and twenty six GPs received the postal questionnaire and the response rate was 64%.

Key Findings

- The responding GPs reported that there were 159 patients within the region with malignant disease currently in need of palliative care (an average of two patients per GP) and 143 patients with non-malignant conditions (an average of two patients per GP).
- GPs most often seek advice from the Specialist Palliative Care Home Team, followed by Special Palliative Care Services In-Patient Units and Acute General Hospitals.
- There were differences across the Board's region with regard to GPs providing services to patients in support beds. Such provision was reported by 14 GPs in Westmeath, five in Laois, seven in Offaly and only one in Longford.
- Cardiovascular and respiratory disease represent the main non-malignant diseases that palliative care services would be required for followed by rheumatoid arthritis/osteoarthritis and multiple sclerosis
- High numbers of GPs neither refer to palliative care services or seek advice from them. Barriers identified included bed shortages (57%), lack of services for non-malignant patients (56%), shortage of ancillary services (36%), lack of specialist advice and support (31%) and out of hours services (18%).
- Nearly all GPs were satisfied with communication with palliative care nurses and 67% were satisfied with communication with community hospitals. Almost no dissatisfaction was reported in these categories. With regard to communication with acute hospitals, 52% of GPs were satisfied, 20% were not and 27% were neither.
- High satisfaction rates were recorded with the Home Care Teams, especially in Longford (78%) and 86% of GPs were satisfied with support received from the Public Health Nursing Services.
- 40% of GPs were dissatisfied with health board re-imburement for services provided.
- 57% of GPs felt that services for palliative care Patients with cancer were inadequate, and this rose to 70% for patients with non-malignant disease.

Section 2: Service Providers

A postal questionnaire was issued to 31 consultants and 89 other service providers in the Midland Health Board. In addition, nursing staff completed questionnaires at focus groups during the qualitative study. The response rate was 60%.

Key Findings

As with the GP survey, respondents praised the effectiveness of the Palliative Care Team in terms of the advice and support they provide, but the majority feeling was that services for palliative care are not adequate within the Midland Health Board.

- Dissatisfaction was expressed with the number of palliative care staff (53%).
- It was felt that there were sufficient beds in community hospitals but not in the acute setting.
- There are few designated beds and some of these are in units for elderly people. This was not regarded as appropriate.
- There are insufficient beds for patients with non malignant conditions.
- There are insufficient respite beds (68%).
- Communication with GPs was satisfactory for almost 60% of respondents.
- Almost half of respondents were dissatisfied with training levels.
- There was high satisfaction with the stage of disease at referral, but occasional late referrals were attributed to lack of awareness of services by GPs.
- Insufficient physiotherapy and occupational therapy services were reported.
- Job satisfaction was generally high (62%) but was affected by lack of resources and structure.
- Availability of advice and assistance was high, this was mainly provided by the palliative care nurse. The need for a Consultant in Palliative Medicine was highlighted.
- Communication with voluntary agencies was satisfactory.
- Seventy-seven percent felt current services were not adequate although the specialist palliative care services that are provided were praised highly.

Stakeholders Perspectives: Qualitative Study

Section 1: Patients and Carers

Seven interviews were held with patients and seven more with carers. Six of the patients suffered from malignant diseases, while one had a non-malignant disease/condition. Three of the carers were bereaved.

Key Findings

The overall reaction to the home care service and the Specialist Palliative Care Nursing Service in particular was overwhelmingly positive. It was regarded as an essential and invaluable service that allows patients to be cared for in their home. Respondents felt it provided the back-up support, security, peace of mind and confidence to both the carers and the patients (*“taking the fear out of minding a patient at home”*).

The Specialist Palliative Care Nurses were perceived as cancer care specialists with greater experience and familiarity with cancer than other health professionals. They were seen to play a central role both from an organisational (co-ordination) and advice point of view, and were typically viewed as “on the side” of the patient. Communication difficulties experienced by patients and carers were often eliminated by the mediation of the palliative care nurse.

The term “palliative care” was often imbued with strong negative associations. This made a few respondents resistant to the service initially, and raises the concern that patients may be missing out on the service or leaving it too late to call in the palliative care team. Patients suggested that the palliative care nurses should have more autonomy, and be allowed to prescribe medication.

Problem areas included:

- There was a general perception that the services are short-staffed.
- Accessing the service could be a problem where the GP was reluctant to refer.
- Most problems had occurred with the acute services and related to *‘bedside manner’* of hospital doctors, to errors and delays. It was noted that beds in centres for older people are not suitable for palliative care patients.
- Respite centres were not an issue for most patients as they do not want to be in hospital.
- Entitlements, and particularly information relating to entitlements, was an area of concern and anxiety for patients and carers. Respondents suggested provision of a booklet with easy to understand instructions, or alternatively, briefing for the palliative nurses with regards to entitlements: patients and carers do not have the time to explore these issues themselves.
- The biggest issues for carers were financial assistance and being *“taken for granted by the system”*.

“I got thick at the start, because I thought they (Palliative Care Nurses) generally come when you are dying ... I gave out stick to the doctor I couldn't do without them now”. (Patient)

“She (palliative care nurse) was out of this world – so sympathetic and caring to him. Its very important to have somebody that cared just as much as you did yourself. She made him feel very comfortable”. (Carer)

“It (palliative care service) takes the fear out of minding a patient at home – it would be a terrible worry if you were on your own”. (Carer)

“They (palliative care nurses) were our lifeline ... hand on heart I could not have survived without them”. (Carer)

“There should be a package put together so people are aware of all their entitlements – both for those with or without medical cards”. (Carer)

“There should be something for carers, they do give a lot of their time. At the moment I can manage, but it may get harder in the long term” (Carer)

There was nobody to turn to when he was diagnosed first, there should be a clinic that doctors can refer you to. At the moment, you just come home and cry”. Carer

Section 2: General Practitioners

Four interviews were held with GPs to supplement the quantitative data from the survey. Diseases covered by palliative care services were mainly cancer related illness. While GPs provide services to patients with non-malignant diseases, they rarely referred these patients to the palliative care services. Some GPs felt strongly that the services should be available to non-malignant patients, while one pointed out that there might be different issues of management, that the condition may be more long term and the needs might be different.

Key findings

GPs praised the Palliative Care Home Team service but felt they needed more financial and staffing support in order to provide faster access. While GPs felt that hospice rooms and palliative care services are available, domiciliary care was considered better for the patient, if possible. Concern was expressed regarding out of hours service, communication from consultants and hospital colleagues. GPs also had concerns regarding the amount of drugs and use of very expensive drugs that were being provided to patients.

"Normally it is something one has to introduce very carefully to the family and to the person themselves concerned. Obviously some patients with cancer can be fine and live a normal life to a large extent. They would only deteriorate very slowly and would only need the physical services of the Palliative Care Nurse literally within a week or two of dying. Whereas other patients don't cope with the physiological end of it and would need maybe more support services. It's very much an individual judgement on each case". GP

"I think Palliative Care Services are like Maternity services, they have to be good. You can't have a waiting list, it isn't like a hip or cataract where you could be waiting for months. GP

"Don't forget that we have known these patients for a long time and are very involved with the families and really you take a huge emotional burden on in a way that the other professionals don't" GP

Section 3: Service providers

Six focus groups and one interview were held with service providers (Palliative Care Nurses, Public Health Nurses and Registered General Nurses).

The service providers were agreed that the Specialist Palliative Care Service that exists in the MHB provides an excellent service to patients, but that overall, the services were not as adequate as they could be.

Key Findings:

- Problems arise because of the stigma and fear which is associated with terminal illness, and therefore, with the palliative care service. There are implications of this for referral and service delivery.
- The development of policies and guidelines for palliative care services in the MHB is essential.
- The development of a management structure for Palliative Care Services is also crucial. The appointment of at least one Palliative Care Consultant and the establishment of a multidisciplinary Palliative Care Team to provide services to both acute and community settings was highlighted.
- Insufficient staffing levels were reported.
- Shortages were noted in relation to occupational therapy services.
- Time should be allowed for increased peer support for staff, as should opportunities for debriefing and seeking advice.
- Emphasis is on care in the home where possible, so a strong focus on community care is necessary for future development.

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"You get to know them from the granny down to the most junior infant. You know the whole family circle as a Public Health Nurse... so we have an advantage. We know who to tap into, what they can cope with". (Public Health Nurse)

"We would pro-actively try to get early involvement (of palliative care nurses) rather than having it at the late stage, so that the family and patient are aware of the services rather than it being kind of, almost when they are ready to go home, and are cramming things into place". (Palliative Care Nurse)

"When people are diagnosed as being terminally ill, then an acute hospital is not a suitable place for them. We have only one single room for them, and after that we try to get them into a long stay unit – we have two for the county with designated hospice beds". (Hospital Nurse)

"You're going into somebody who is very ill, to be asking for a deposit of twenty euro for a commode". "It's a terrible thing because you're talking about money at a time of grieving." (Palliative Care Nurse)

"I think one of the greatest difficulties for a lot of our patients is having to be admitted through casualty, now if it's during the day time, and we can access our colleagues (in the hospital)) it's actually fantastic...but it is a problem, you know, for a really ill patient to spend many hours in casualty" (Palliative Care Nurse).

"A lot more patients were coming out with maybe central lines even though we would have asked for in-service training on that in the community over four years ago, we haven't got that. So anybody who's out there in the community is expected to you know, maybe flush a line or whatever, keep it patent, and yet we're haven't had any training on that". (Public Health Nurse)

"The consultants will quite often refer to the Palliative Care Nurse Specialists for advice as regards pain control and whatever...and sometimes I feel that the Palliative Care Nurse Specialists are a little bit swimming on their own. I mean if they have a problem where do they go? They can't go back to the same consultant because they don't know". (Hospital Nurse)

"We don't have a policy to follow, so if something goes wrong we have nothing backing us up, you can't say 'well I followed the policy' because there isn't one". (Palliative Care Nurse).

"The patient may need support from the time they are told of their diagnosis throughout the illness. They then need to go through the adjustment of needing various health professionals calling to their home, and they go through a range of different emotions at this time. Listening and counseling skills are crucial. There may be other family problems that come to the surface at this time, or the illness itself may cause problems for others in the family. There are often financial problems in a home when a member is seriously ill". "All of that can cause a lot of mental torment and the mental anguish can be worst of all".(Palliative Care Nurse)

"In the strategy they had hoped to have, we'll say a specialist unit with satellite beds but we certainly also need very localised beds in local areas". (Hospital Nurse)

Identified Needs

This section summarises the needs identified in both the quantitative and qualitative parts of the needs assessment.

Structure and Staffing

- A Specialist Palliative Care Unit is required in the Midland Health Board with inpatient, long-stay and respite facilities; provision of palliative care services using the acute setting and beds in centres for older people was not considered appropriate. Small specialist units attached to, but separate from the acute hospitals may be appropriate.
- Co-ordinated approach - multidisciplinary team led by a Consultant in Palliative Medicine with improved links to oncology services.
- More specialist palliative care nursing staff
- Out of hours and weekend / 24 hour service with appropriate remuneration for staff was highlighted. This also would require additional staff, especially twilight and night nurses
- Some respondents felt that there should be increased involvement of public health nurses
- Training and education is required for both specialist and non-specialist staff.

Communication

- Communication systems and channels to facilitate multidisciplinary involvement in services need to be developed. Some thought that there was a need for better communication with all services, but particularly acute hospital services
- There is a need for referral protocols. Hospital referral procedures to specialist palliative care are not uniform, and GPs are sometimes reluctant to refer to the specialist services. Hospital Admission policies also need to cater for special needs of patients by fast-tracking their admission procedure
- Protocols should also be developed for treatment and inter-disciplinary involvement
- There is a need for a liaison person in the acute setting to communicate with the community including the GP.
- The need for clarification of roles of all health professionals involved was identified.

Generic Palliative Care

- There is a need for bereavement counselling for families, staff and GPs.
- Other service needs identified included: respite services in each community care area, counselling and social work services; family support, increased physiotherapy and occupational therapy involvement (shortages were noted in relation to occupational therapy services).
- More palliative care services for non-malignant patients
- A need for financial assistance to patients and their families was reported.
- The information needs of patients with regard to financial services and entitlements should be met.
- A Directory of Services should be produced for all aspects of care

Recommendations

Structure

When the recommendations of the National Report are applied to Midland Health Board Data, the recommended number of inpatient beds is 20/22. This is in addition to the number of general palliative care beds already in the community. The number of inpatient beds in Longford/Westmeath needs to be increased as there are only three of these, provided by the Board in Longford/Westmeath, and a further one funded by Longford Hospice Agency.

Specialist Palliative Care Unit

According to the National Report, the population of the Midland Health Board requires one specialist palliative care unit. This should be sited close to oncology services and also be geographically accessible to all areas of the Health Board.

Community Satellite Base

Community services for the adjacent community care area should be based in the specialist unit. It is recommended that a community satellite base be established to serve the other community care area. Day Care centres should be established in both units.

Staffing

Specialist Unit

- 2 Consultants in Palliative Medicine
- 6 Non-Consultant Hospital Doctors
- Co-ordinator (also to act as link person)
- 20 WTE Specialist Palliative Care Nurses plus leave relief
- 2 Physiotherapists
- 2 Occupational Therapists
- 2 Social Workers
- 1 Psychologist
- 2 Chaplains
- 1 Pharmacist
- 10 Care Attendants
- 1 Volunteer Co-ordinator
- 1 session per week from Speech and Language Therapist, and/or Clinical Nutritionist
- Alternative Therapy

Acute Hospital: Midland Regional Hospital at Mullingar, Portlaoise and Tullamore

- 1 WTE Specialist Palliative Care Nurses in Mullingar
- 1 WTE Specialist Palliative Care Nurses in Portlaoise plus leave requirement
- 2 WTE Specialist Palliative Care Nurses in Tullamore

Day-Care

One WTE Specialist Palliative Care Nurse for every 7 day-patients.
The acute hospitals will be serviced by the main unit and/or acute ancillary team services as appropriate.

Community Palliative Care Services

The recommendation of the national report is 1 Specialist Palliative Care Nurse per 25,000 population. This implies the following requirements

- 2 Co-ordinators – CNM specialists (also to act as link person)
- 12 WTE Specialist Palliative Care Nurses: 6 in Laois/ Offaly, 6 in Longford/Westmeath.

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- 2 Physiotherapists: 1 in Laois/ Offaly, 1 in Longford/ Westmeath.
- 2 Occupational Therapists: 1 in Laois/ Offaly, 1 in Longford/ Westmeath
- 2 Social Workers 1 in Laois/ Offaly, 1 in Longford/ Westmeath.
- Clerical and information technology support
- Access to counselling (see community model below)

Generic Palliative Care

- Regional policy on palliative care to be developed by a Regional Committee on Palliative Care in conjunction with Specialist Palliative Care Team.
- Protocols to be developed for audit and quality assurance.
- Protocols and guidelines to be developed for the following by the Specialist Palliative Care Team in conjunction with service users:
 - Referral
 - Admission
 - Treatment
 - Communication
- Directory of Palliative Care Services to be developed - overseen by Palliative Care Team
- Directory of entitlements to be developed - overseen by Palliative Care Team
- Appropriate financial assistance should be provided to patients and their carers.
- Appropriate information technology should be provided
- Education and training should be planned and implemented by the Specialist Palliative Care Team.
- A health promotion campaign should be developed to raise public awareness and to counter fear and stigma. This should focus on quality of life for patients and should develop the understanding of the role of palliative care in achieving this.

Community Model – Based on the Principles of Shared Care

Palliative care services in the MHB have depended heavily on the Specialist Palliative Care Nursing service which is community based with links to acute and primary care services. Therefore it is recommended that services should develop based on a community model operating on the principles of shared care.

Structure

- One community satellite base should be established at Mullingar
- The service should be consultant led: one consultant should cover Longford/Westmeath although both could be based in the main specialist unit.
- The main specialist unit in Tullamore will cater for Laois/ Offaly
- Co-operation and collaboration with voluntary agencies

Staffing

- There should be a co-ordinator at each base: CNM III
- There should be 6 WTE Specialist Palliative Care Nurses at each base (12 in total)
- There should be one Social Worker at each base (2 in total)
- Clerical support will be required at the Mullingar base
- Two Physiotherapists should be appointed: one to cover Laois/ Offaly and one to cover Longford/ Westmeath. Both should be based in the main Specialist Unit.
- Two Occupational Therapists should be appointed, one to cover Laois/ Offaly, and one to cover Longford/ Westmeath. Both should be based in the main Specialist Unit.
- There should be adequate provision of Registered General Nurses, Twilight Nurses and Night Nurses.
- Home Care Attendants and /or Trained Carers should be provided where required.

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Service provision

- The Specialist Palliative Care service should operate on a 24-hour basis, 7 days a week.
- The contracts of Specialist Palliative Care Nurses should be formalised.
- An appropriate supply of aids and equipment should be maintained by the Board
- The practice of seeking a 20 Euro deposit on equipment from patients for equipment should cease
- Expensive drugs and equipment should be deemed budget neutral by the Department of Health and Children.
- The Unit Pharmacist should link with Community Pharmacists regarding procurement of drugs not regularly stocked. Early notice of the need for these drugs should be given to pharmacists in the community.
- One designated Community Welfare Officer in each community care area should have a role in the provision of financial assistance and information on entitlements and should link with the social worker.
- Appropriate transport should be provided by the Board, where necessary to allow patients to avail of Palliative Care Services.

A Culture of Palliative Care – Community Model

