

# ECONOMIC EVALUATION OF PALLIATIVE CARE IN IRELAND

2015

## AUTHORS

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“Evidence from this study shows that more developed palliative care reduces the cost of other health services. While overall savings are probably not achieved, much of the cost of palliative care can be paid for by savings from hospital care.”

PROFESSOR CHARLES NORMAND

## INTRODUCTION

This research report examines evidence on the cost and cost effectiveness of alternative models of specialist palliative care (SPC) in three regions in Ireland. The research was carried out by a team from Trinity College, Dublin and the Economic and Social Research Institute, led by Professor Charles Normand, Edward Kennedy Professor of Health Policy and Management at Trinity College.<sup>1</sup>

The objectives of the study were to:

- Examine total formal and informal care costs per patient in receipt of SPC over the last year of life;
- Measure certain outcomes for patients in receipt of SPC (including accessibility, quality of care, location of death, palliative care outcomes and quality of life);
- Examine the patterns of costs and outcomes for different models of palliative care.

## RATIONALE

Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness by early identification and assessment and treatment of pain and addressing physical, psychosocial and spiritual needs.

Although palliative care provision has been expanding worldwide, evaluation of SPC that has an economic focus has been slow to develop and the evidence base remains small. Filling this evidence gap is increasingly important to facilitate good resource allocation decisions.

The international literature on economic evaluation in palliative care across different types of studies finds that palliative care is often statistically significantly less costly, though these studies focus mostly on formal care costs.<sup>2</sup> This study contributes to the evidence base on the costs and outcomes in palliative care by drawing on variations in how services are organised in Ireland and by examining both formal and informal care costs, combined with an analysis of a range of patient outcomes.

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<sup>1</sup> The research team also included Dr Aoife Brick, Research Officer, ESRI; Dr Samantha Smith, Research Analyst, ESRI; and Ms Sinéad O'Hara, Data Analyst, ESRI. Dr Brick and Dr Smith both hold adjunct positions at the Department of Economics, Trinity College Dublin.

<sup>2</sup> 'Formal care costs' are defined as the costs directly related to the provision of healthcare by formal providers (e.g., hospitals). 'Informal care costs' refer to care provided by family and friends of the patient.

## APPROACH

The research examined variations in the mix of specialist palliative in-patient, day and home care in Ireland. The regions examined included the HSE Midlands Area (incorporating Laois, Offaly, Longford and Westmeath), the HSE Mid West Area (incorporating Clare, Limerick and North Tipperary) and the HSE South East Area (including South Tipperary, Waterford and Wexford, excluding Carlow/Kilkenny).

**Formal and informal costs of care were examined for a sample of patients who had received SPC in the last year of life.** These were assessed by interviews with key informants and other data sources. (A key informant is a person involved in the patient's care and decision-making in the last year of life, normally next of kin or a friend.)

**The patient experience was assessed through interviews with the key informants.** The levels of accessibility and quality of care, preference about location of death and health-related quality-of-life in the last year of life were examined.

**The research focused on patterns and systematic variations in costs and outcomes across the different models of care to inform policy decisions on resource allocation to and within palliative care services.** Rather than adopting standard economic evaluation techniques, careful examination of the formal and informal costs of care across different models of SPC in the three regions was drawn together with the analysis of patient experiences.

## KEY FINDINGS

### PALLIATIVE CARE SERVICES IN IRELAND

**The research found wide variations in the availability of SPC services in Ireland.** While all areas have access to specialist community palliative care/home care teams, not all have access to a SPC in-patient unit, specialist palliative day care centres or outpatient clinics attached to SPC units. There are eight dedicated SPC in-patient units, with nine Local Health Offices having no such unit and no access to specialist in-patient beds. The staffing levels of in-patient units vary, as waiting lists exist for admission to some units and not others.

**Differences also exist in the way services are structured and resourced.** Most community SPC teams are consultant-led, multidisciplinary services, while in some areas they are nurse-led. Availability of services vary from 24 hours a day, seven days a week, to office hours only and there are further variations in staffing levels of teams. Insufficient home help and public health nursing capacity can make patient care in the community hard to maintain, resulting in in-patient admission. Most SPC hospital teams provide services five days a week and round-the-clock telephone advice for hospital staff, general practitioners (GPs) and community services. There are large variations in the staffing levels of the SPC teams in acute hospitals. The voluntary sector contributes significantly to all aspects of palliative care in Ireland, including in the three study areas.

**The study areas have different levels of development of SPC services and, to an extent, different models of care.** The Mid West has a facility with in-patient and ambulatory palliative care services, while in the Midlands and South East, SPC services are mainly provided on an outreach basis in people's homes.

## COMMUNITY CARE SERVICES

**In the end-of-life period, there is a tendency for SPC services to replace other forms of healthcare.** GP visits decrease in the last three months of life which may reflect more use of community SPC nurses and public health nurses as well as increased institutional care.

**Most patients did not use allied health professional services in community settings, which may reflect shortages of such staff and difficulty in gaining access** – a finding that suggests potential benefits in making these services available via day care services and outpatient /walk-in facilities (e.g., in the Mid West patients can receive these services as part of SPC day care and in-patient hospice services).

**The most widely used paid help in the home was home help,** reflecting the importance of home help in enabling patients to stay in their own home.

## SPECIALIST PALLIATIVE CARE

**Where SPC is well developed and its role well understood, more and earlier referrals are likely.** Earlier referral may improve patient experiences. It increases the chance of orderly transition from curative to palliative services. There is evidence from other studies that patients who are referred earlier are more likely to have fewer high cost interventions and may have better quality of life. The patterns of use of community SPC services were similar in each area, with the intensity of use higher in the last three months of life.

**SPC services are appropriate for many people only in the last few weeks of life but there is substantial variation in the timing of referral to SPC across the three study areas.** Almost 70% of patients in the Midlands were referred in the last three months of life, compared to 61% in the Mid West and 58% in the South East.

## HOSPITAL CARE

**More than a third of patients in each area were admitted as hospital day patients and/or had in-patient hospital stays in the first nine months of their last year of life.**

**While it was not possible to say whether admissions to acute hospitals were appropriate, there is evidence that many admissions are not appropriate and reflect the lack of viable alternatives.** The study shows that where in-patient hospice services are available, the level of admissions to acute hospitals is significantly lower in the last three months of life. While hospice beds and hospital beds are not exact substitutes, when no hospice bed is available there is more chance of a hospital admission. It is reasonable to argue that experiences of patients will be better where hospice services can prevent some hospital admissions.

## INFORMAL CARE

**Informal carers play an important role in caring for the patient in the last year of their life.** They include anyone who helped care for a patient at home on a regular basis (e.g., washing, dressing and household tasks). In the Midlands and Mid West, a high proportion of primary carers were the spouse or partner while in the South East, a larger proportion were children of the patient. The majority of primary carers in all areas were women aged 35-64.

**When spouses are providing informal care, in each area they tend to provide the majority of this care.** On the other hand, children and others providing care tend to share the caring duties. The proportion of patients needing informal care and the intensity of that care is generally higher in the last three months of life. The most intensive forms of care provided by carers in the last three months of life were household tasks, followed by personal care and eating and drinking. Patients in the South East were most dependent in terms of caring time required each day.

## TOTAL FORMAL AND INFORMAL CARE COSTS PER PATIENT

**The costs of palliative care was similar in each region despite the considerable variations in services.** Average total formal costs across the regions ranged from €40,000 (South East) to €50,000 (Midlands and Mid West) in the last year of life. The average total informal costs for this period ranged from €14,000 (Midlands) to €18,000 (Mid West). The average total formal and informal costs in the last year of life ranged from €56,000 (South East) to €67,000 (Mid West). The costliest component of care in the Midlands and South East was hospital care followed by informal care. This contrasts with the Mid West where the most costly component of care in the final three month period was SPC, followed by hospital care and informal care.

**The ability to access in-patient hospice beds may lead to savings within hospitals in the last three months of life and reduce inappropriate hospital admissions.** While the variation in average hospital costs across the regions during the first nine months of the last year of life is not significant, it is statistically significant in the final three months.

## KEY OUTCOMES

**Most patients and their carers reported that getting access to community SPC or hospice care, where it was available, was either fairly or very easy, while they found accessing a bed in hospital when needed more difficult.** This was particularly the case in the Mid West and Midlands, where almost 40% and 35% respectively reported that getting access to a hospital bed was 'fairly difficult' or 'very difficult'. This finding may be important given the emerging evidence from other studies that people are very stressed by process difficulties in accessing care near the end of life.

**Poorer levels of perceived quality (including acceptability of death and emotional support) of in-patient hospital services when compared to SPC services were also identified in the data.** Symptom management in hospital care was highly rated. In each area, people were most satisfied with the quality of care from the community SPC despite the diversity of how these services were delivered. This finding may reflect underlying problems in the experience of hospital care and a more general perception of the inappropriateness of the acute hospital setting for many people nearing the end of life.

**In the Mid West, the only area where both in-patient hospice and in-patient hospital services were available, the hospice scored higher than hospital care on every quality measure.** In other areas, people had only experienced one kind of service and rated quality levels without being able to compare that service with hospice care.

**In many cases an important objective is for the patient to die in a preferred location, though that preference may change during the course of an illness.** Six months prior to death, most individuals in all areas wanted to die at home. However, by the last week of life this proportion had decreased in all areas, most likely reflecting an individual's increasing level of need and wish not to place this burden on family. Almost 75% of patients in the study died in the location for which they had stated a preference in the last week of life. In the Mid West, where in-patient hospice services are available, more patients died in the hospice setting and fewer in hospital.

**These outcome measures point to the desirability of facilitating in-patient hospice use as an alternative to in-patient hospital care where appropriate.**

## CONCLUSIONS

While the study did not find evidence of advantages of different models (e.g., allied health professionals working in day care or outreach settings), it points to the possibility of cost and access advantages where access to a range of services in a day care setting is co-ordinated. The study shows that there is a reduction in use of in-patient hospital care where hospice beds are available but the overall costs of care are slightly higher where there is a fuller SPC service. The effects on informal care burden are not clear and, in all cases, the costs and time commitment from informal care is high. It would be interesting to know whether increased formal care could reduce that burden.

There are high levels of satisfaction with SPC services in all study areas. Patterns of service delivery and use vary across the three areas, with slightly higher costs where SPC services are more developed, but more services provided by SPC reduce use of other health services.

There is a need for more advanced measurement tools to compare costs and experiences in palliative care, in order to allow comparison of different models of care.

The full report can be found here:

[https://www.researchgate.net/publication/281406801\\_Economic\\_Evaluation\\_of\\_Palliative\\_Care\\_in\\_Ireland\\_-\\_Final\\_Report](https://www.researchgate.net/publication/281406801_Economic_Evaluation_of_Palliative_Care_in_Ireland_-_Final_Report)

A companion report on the results of a literature review on the cost and cost effectiveness of palliative care can be found here:

<http://pmj.sagepub.com/content/early/2013/07/05/0269216313493466.full.pdf+html>