

Economics of Palliative Care: Evidence and Impact from Four Recent Studies

A report for The Atlantic Philanthropies

By Bridget Johnston, Charles Normand and Peter May

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Contact

Palliative Care Economics (PaCE) Research Group
Centre for Health Policy and Management, Trinity College Dublin
3-4 Foster Place
Dublin 2
Ireland
E: bjohnst@tcd.ie | pemay@tcd.ie

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Summary

This report presents findings from four recent, innovative economic studies of palliative care. Three of the studies were funded by The Atlantic Philanthropies; the fourth was funded by the National Cancer Institute (NCI) and National Institute for Nursing Research (NINR) in the United States, with the economic analyses conducted through an Atlantic Philanthropies-supported research collaboration.

Key findings and policy implications from these studies are:

- Palliative care policy should be based on evidence of patient preferences, which may differ from the preferences and assumptions of both patient caregivers and health system decision-makers.
- People accessing palliative care often receive significant support from family and informal caregivers, which all have a cost implication for society. Failure to take all relevant costs into account may result in preference being given to interventions or models of care that shift a larger proportion of costs onto patients and caregivers.
- Long-term policy considerations must include potential payment mechanisms to reward informal care and reduce unnecessary formal health care utilisation, but also target people who live alone or in isolation, who cannot avail of informal care, and may be underserved and at greater risk of adverse outcomes as a consequence.
- Timely palliative care following hospital admission for adults with advanced cancer is associated with lower cost of care, and this association is stronger when the intervention is provided earlier in the admission. All else being equal, palliative care teams should be involved in the care of seriously ill people promptly following admission.
- The cost-effectiveness of hospital palliative care appears to be greater for adults with higher illness burden. It is the sickest patients for whom the impact is greatest, and so it is they who should be prioritised for scarce palliative care resources.
- For both patients who receive palliative care and those who do not, illness burden is a consistent driver of utilisation during hospitalisation. In a context where a small number of complex patients account for disproportionate levels of healthcare costs, palliative care may be a more effective tool than previously realised in improving care and curbing cost growth among the sickest patients.
- Shorter length of stay arising from hospital palliative care must be matched by appropriate post-discharge services to ensure that savings made in the hospital are not simply passed on to the patient and their family.

1. Introduction

A global priority

Governments and public policymakers around the world are interested in the economics of care for people with serious illness and functional impairment (1-3). There is a well-known ‘high costs, poor outcomes’ pattern among this population: people living and dying with life-limiting conditions account disproportionately for health budgets yet their care is often fragmented, inconsistent with patient preferences, and results in poor outcomes (4). **Given population ageing worldwide and associated care needs, it is essential to both improve quality of care and curb cost growth if older people with serious illnesses are to live and die with dignity (5).**

Palliative care is the multidisciplinary speciality that aims to improve the experience of seriously-ill people and their families by focusing on quality of life and providing information with which to make choices and establish goals (6, 7). Research to date suggests that palliative care is associated with improved patient and family outcomes and in some cases extended survival (8-11), but the evidence base remains relatively small because the conduct of such studies faces a number of serious challenges (12-14).

The Atlantic Philanthropies and palliative care in Ireland

The Atlantic Philanthropies (Atlantic) made a major investment in Irish palliative care at the start of the 21st century in its end of Life programme. Projects included a new inpatient hospice at Marymount, Cork; a new homecare service from Milford Care Centre, Limerick; and the All-Ireland Institute for Hospice and Palliative Care, an all-island hub for education, research and policy based at Our Lady’s Hospice in Dublin city (15).

A 2011 review catalogued a series of major accomplishments by the programme, and by palliative and hospice care on the island more generally (16). Ireland has a long history of palliative care driven by the voluntary sector (17) and consistently appears near the top of international rankings of palliative and end-of-life care (18, 19).

A critical gap in the evidence

However, the review also identified important deficits and barriers to further progress. One key obstacle was a lack of economic evidence on services both within Ireland and internationally (16). Advocacy groups in Ireland had played an important role in driving the creation of a dedicated national policy in the early 2000s and subsequent expansion of services, including some uses of economic data (20, 21). But the Irish Department of Health remained resistant to fully embracing palliative care and establishing nationwide provision of such care on the basis of need due to a lack of relevant, high-quality evidence on the costs and benefits of such a proposal (16, 22, 23). Consequently access to palliative care in Ireland continues to depend substantively on where the seriously-ill person lives (24, 25).

From some perspectives within palliative care, the economic arguments are subordinate to the ethical ones (26). However, to economists and policymakers there is no meaningful distinction. **Any additional funding provided to palliative care is money that could otherwise be spent on other parts of the health system or public service. Resources must be allocated where they yield the greatest benefit and it is therefore essential that the value of palliative care is demonstrated alongside other treatments and interventions.**

Economics of palliative care: four recent studies

This report documents four analyses of palliative care in recent years that, with the support of Atlantic, have begun to address this barrier to palliative care’s development in Ireland and internationally:

1. **Economic Evaluation of Palliative Care in Ireland (EEPCI).** In response to the 'End of Life programme' review detailing the need for economic evidence to drive policy impact, Atlantic funded the EEPCI project through the Centre for Health Policy and Management at Trinity College Dublin (TCD). First, EEPCI researchers conducted a systematic review of all economic evidence on palliative care to date, establishing a benchmark for all subsequent studies and for decision-makers in health systems. Second, they conducted research on the service use and experience of palliative care in three regions of Ireland in order to understand how patterns of care, costs, and outcomes varied according to individual characteristics and local access.
2. **International Access, Rights and Empowerment (IARE) study.** The challenges posed by a growing older population with increasing prevalence of multimorbidity, frailty, and dementia are faced by nations around the world. In recognition of this fact, and capacity of international comparative research to leverage insights across countries and systems, Atlantic funded the IARE study at TCD, King's College London (KCL), Icahn School of Medicine at Mount Sinai (ISMMS) and University of California at San Francisco (UCSF). IARE was conducted in hospitals in Dublin, London, New York, and San Francisco, and aimed to improve the rights of older palliative care patients (≥ 65 years) and their carers by gathering information about access to and empowerment of people requiring specialist palliative care in order to help secure equitable access to healthcare for this population.
3. **International Access, Rights and Empowerment Plus (IARE Plus) study.** The IARE Plus study aimed to extend the evidence on preferences developed through the IARE study by gathering information about the needs, experiences, and preferences of people living with a life-limiting illness and those who care for them. This study was carried out across three sites in Ireland in order to explore potential differences linked to age, location, and self-reported knowledge of palliative care services. This work was funded within a structured research network at the All Ireland Institute of Hospice and Palliative Care (AIHPC). The AIHPC was formally established in October 2010, following a successful bid by consortium members to secure funding for the organisation from Atlantic.
4. **Palliative Care for Cancer Study (PC4C).** The original PC4C study was funded by the National Cancer Institute and National Institute for Nursing Research in the United States. This was a four-year study at five U.S. hospitals of palliative care consultation (PCC) impacts for adult in patients with advanced cancer. The lead centre for the PC4C study was ISMMS in New York. In the context of the fruitful IARE collaboration, health economists at TCD partnered with clinicians at ISMMS to conduct economic analysis of the PC4C data. The subsequent research outputs have established a new benchmark in economics of PCC in the U.S. and enabled identification of new and important associations between PCC and costs with research and policy implications internationally.

2. Key Findings of Four Recent Studies

2.1 Economic Evaluation of Palliative Care in Ireland (EEPCI)

Background

Economic evaluation has become an important tool for health policy because it facilitates the description and comparison of costs and benefits of competing uses of resources within a common framework. Despite increased emphasis on establishing value for money, the evidence base for the cost effectiveness of palliative care interventions remains limited. This reflects the methodological challenges in capturing information about all the relevant costs and activities, in addition to identifying, measuring and valuing outcomes (27, 28).

However, against the backdrop of increased competition for limited resources, studies must begin to accurately measure the cost-effectiveness of palliative care. **Evidence from economic evaluations would not only make it possible to assess the value for money of palliative care relative to other interventions, but also whether the service models funded are the most efficient use of resources.** Otherwise there is a risk that these services may lose out in the competition for resources to those with better evidence about their cost-effectiveness.

The need for economic evidence to influence palliative care policy in Ireland was highlighted by the end of life programme review (16). In response, Atlantic funded the EEPCI study to generate evidence on the cost and cost-effectiveness of alternative models of specialist palliative care (SPC) provision (e.g., variations in availability of specialist palliative day, in-patient, and home care services) in three regions of 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.

Methods

The EEPCI study focused on costs and outcomes in the last year of life and the factors which may influence these; however, particular attention was given to the last three months of life. There were two phases to the project. During the first phase, the research team conducted a systematic review of all available economic evidence on palliative care interventions in any setting. The second phase involved primary data collection on formal and informal costs and outcomes in the last year of life through telephone interviews with bereaved caregivers directly involved in providing care during the last year of life (29). In total, 215 caregivers were interviewed.

The EEPCI study adopted a societal perspective, meaning it considered costs incurred by public health services and private individuals. Formal costs were calculated for community, SPC, acute hospital and other services. Hours of informal care provided (e.g., hours of assistance with basic activities of daily living and instrumental activities of daily living) were valued at the cost of replacing with formal services. Reported out-of-pocket payments such as non-prescription drugs, equipment, and home modifications were also included. Whenever possible, a bottom-up approach (i.e., multiplying utilisation by unit cost) was used to determine formal costs. The analysis drew on a wide range of administrative data sources to generate unit costs for formal care services.

The regions examined included the Health Service Executive (HSE) Midlands Area (Laois, Longford, Westmeath, and Offaly), the HSE Mid-West Area (Limerick, Clare, and North Tipperary) and the HSE South-East Area (South Tipperary, Waterford, and Wexford, but excluding Kilkenny/Carlow). There are differences in the level of development of SPC services across the study regions. The Mid-West has a SPC unit (hospice) with in-patient and ambulatory services, in addition to SPC services in peoples'

homes (home care). In the Midlands and the South-East, SPC services are mainly provided through home-care teams.

Results

Phase 1

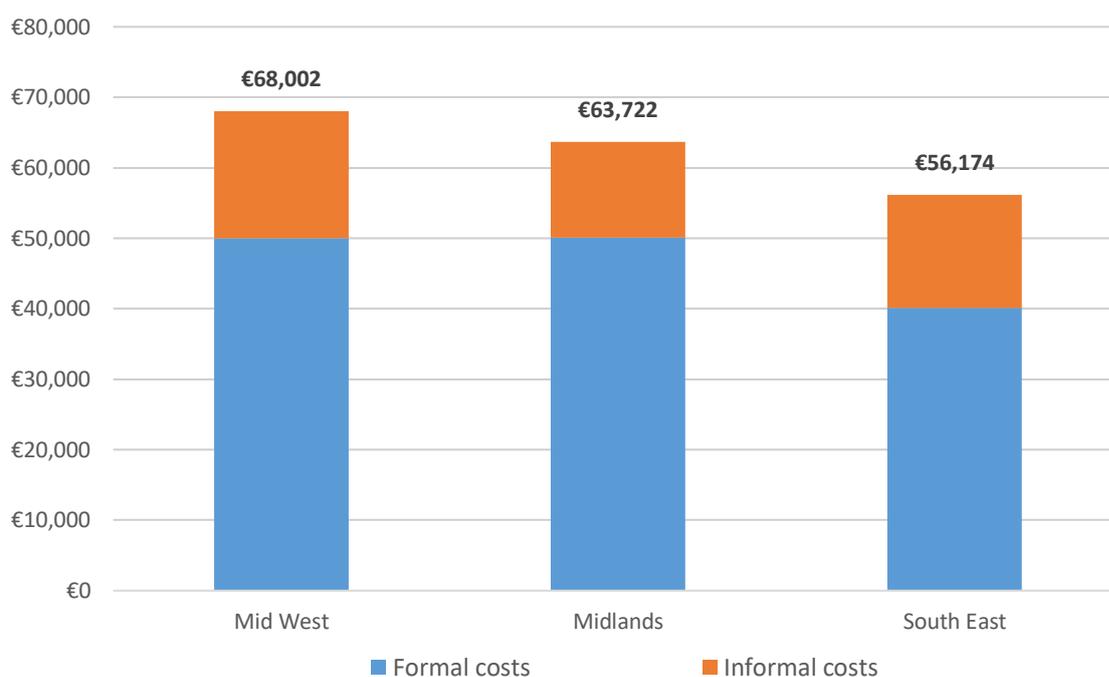
The systematic literature review identified 46 papers that compared either the cost implications or the cost-effectiveness of palliative care interventions relative to a comparator. While there was wide variation in study design and quality, the results demonstrated that palliative care is usually found to be less costly relative to the comparator groups. However, the studies identified had important limitations, thus reducing their potential for guiding policy. First, they focused primarily on direct costs (i.e., those incurred by the healthcare system or third-party payers), leaving out-of-pocket costs and informal care provision unexplored. This is a significant gap in knowledge, given that people accessing palliative care services often receive substantial support in the community from loved ones. Second, because of concerns that health-related quality-of-life measures do not fully capture the relevant impact of palliative care, studies usually considered costs without measuring outcomes. **These data on outcomes are necessary if conclusions are to be drawn about the cost-effectiveness and value for money of these interventions.**

This work was published in *Palliative Medicine*, the research journal of the European Association of Palliative Care, in 2014 and has since garnered significant attention. It is the most cited article from the journal in the last three years and was named their 'Research Paper of the Year' for 2014.

Phase 2

Average total formal and informal costs across the three regions are shown in Figure 1. Average total costs of formal care in the last year of life across the regions ranged from approximately €40,000 (South-East) to €50,000 (Mid-West and Midlands). Average total costs for informal care and out-of-pocket payments ranged from about €14,000 (Midlands) to almost €18,000 (Mid-West). The average total costs for both formal and informal care ranged from €56,000 (South-East) to €68,000 (Mid-West). These differences in costs are not statistically significant ($p = 0.136$).

Figure 1 Mean formal and informal cost in last year of life, by study region



There was, however, notable variation in the patterns of service utilisation, particularly around acute hospital and specialist palliative care services. The costliest component of formal care throughout the last year of life in the Midlands and the South East was hospital care. A different pattern emerges in the Mid-West, where palliative care services were the costliest component of formal care in the last three months of life (42.5%), followed by acute hospital care (32.2%). The ability to access in-patient hospice beds in the Mid-West may help explain why lower hospital costs and reduced utilisation are observed in this region.

Mean total Informal costs in the last year of life did not vary significantly between the three study regions ($p = 0.312$). These ranged from €13,651 in the Midlands (21.4% of total mean costs), to €16,037 in South-East (28.9%) and €17,966 in the Mid-West (26.4%). Overall, mean costs for personal care and assistance with household tasks account for the largest proportion of informal costs in the last year of life. Interestingly, informal costs were highest in the Mid-West, which also had the highest formal costs. This suggests that formal care and informal care act as complements to each other, not substitutes.

Key findings

- The literature review found limited economic evidence about palliative care, with only one study evaluating both costs and outcomes.
- Formal and informal costs in the last year of life for people accessing specialist palliative care services are considerable. Despite differences in the model of care, this variation in costs was not statistically significant.
- There was no evidence of advantages in terms of costs or outcomes of any model of care.
- The EEPCL study identified important differences in patterns of service utilisation, mainly reflecting regional variation in availability. Provision of comprehensive specialist palliative care services in the Mid West (i.e., in-patient hospice beds) appeared to reduce utilisation of

acute hospital services near the end of life. And while the proportion of people dying at home was similar across the study regions, the availability of in-patient hospice services also meant that fewer decedents in the Mid West died in hospital.

- This variation in service utilisation and place of death may reflect important differences in patients' and families' experiences.
- Informal care accounts for a high proportion of costs during the last year of life, underscoring the important role of caregivers in palliative care.

2.2 International Access, Rights and Empowerment (IARE) study

Background

As average life expectancy increases across the developed world, growing levels of chronic disease will pose significant challenges for ageing people, health care systems, and economies. With nearly a quarter of the world's disease burden (23%) attributable to people over the age of 60 (32), it is crucial to understand the experiences, needs, and priorities of older patients. There is a need not only to improve health by addressing disease and disability in this population, but to also focus on promoting quality of life and enabling people to live well.

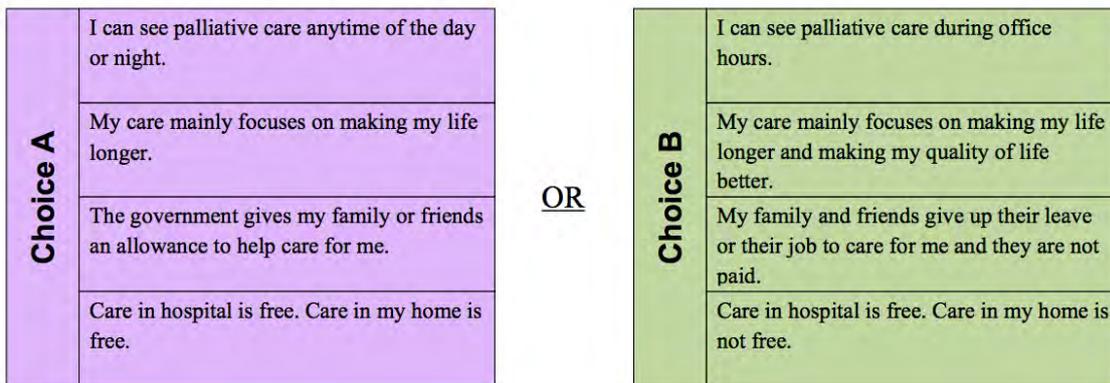
The IARE study was carried out in Ireland, the U.K. and the U.S. with the aim of improving the rights of patients over the age of 65 accessing specialist palliative care services, and their families, through better understanding their needs and the factors that help or hinder access to services. To date, palliative care has been offered as a bundle of services provided by interdisciplinary teams– primarily by hospitals and hospices. There is limited evidence available to aid in the development of models of palliative care provision or to assist in making decisions about which elements and characteristics of palliative care service provision should be prioritised. The IARE study was the first of its kind to focus on older patients' preferences for support when accessing palliative care services.

Methods

The study comprised three work packages. Work package one collected data on patients' needs and experiences through face-to-face surveys. A discrete choice experiment (DCE) – a survey tool that asks individuals to make trade-offs between two or more hypothetical packages of care – was undertaken during the interviews to evaluate preferences for services and supports and the factors that influence their priorities.

Participants were shown 6 cards and asked to choose between packages of care with various attributes representing elements of the palliative care services and supports. Scenarios combined positive and negative attributes of the service. An example of one of the choice sets is shown in Figure 2. DCEs offer a useful approach to priority setting and are an established method for evaluating preferences related to process or other attributes of care not specifically captured using health-related quality of life measures. This is important in the context of palliative care, where interventions are tailored towards providing satisfactory longitudinal experiences rather than reductions in mortality or morbidity.

Figure 2 Example of a choice set used in the DCE



Work package two was an ethnography. The research team conducted in-depth interviews with patients with advanced disease, family caregivers, palliative care staff, and other health professionals caring for older adults with advanced disease in hospital settings and field work (e.g., participant and general observation and collection of artefacts). Further details on the results of this component of the study were reported by Selman et al. (33).

Work package three used a follow-back postal survey with bereaved caregivers to capture data on patients' health and social care utilisation and experiences in the last three months of life when accessing palliative care services. Caregivers were also asked to report their own experiences and satisfaction with care. Formal care costs were calculated using a bottom-up approach. Regression analysis was used to identify factors associated with reported costs.

Results

Economic evidence was generated primarily through the surveys with patients and bereaved carers.

Patient survey

Of 77 patients interviewed in Dublin and London, 51 participated in the DCE component of the interview (response rate=66%). The results of the analysis are presented in Table 1. The coefficients estimate the weight of preference placed on the particular attribute level and its influence on participants' choices. A positive coefficient for an attribute level suggests that participants preferred it relative to its reference level. Attribute levels with a confidence interval that did not include zero and had a p-value of less than 0.05 were deemed to have a statistically significant influence on patients' preferences. The attributes included in the DCE were: 1) availability of services; 2) focus of care; 3) financial support for informal carers; and 4) cost of care in the home.

Table 1 Results from the DCE

| Attributes and levels | Coefficient (95% confidence interval) | P value |
|---|--|---------|
| Availability of the palliative care team | | |
| <i>During office hours*</i> | - | - |
| Anytime day or night | 0.47 (0.24 - 0.71) | <0.001 |
| Focus of palliative care | | |

| | | |
|---|--------------------|--------|
| <i>Making life longer*</i> | - | - |
| Making life longer and quality of life better | 0.49 (0.22 - 0.75) | <0.001 |
| Making quality of life better | 0.54 (0.27, 0.81) | <0.001 |
| Unpaid caregiver support | | |
| <i>Family take time off and lose pay*</i> | - | - |
| Care provided from free time only | 0.54 (0.25 - 0.85) | <0.001 |
| Family take time off and receive government allowance | 0.51 (0.23 - 0.80) | <0.001 |
| Cost of care | | |
| <i>Home care is not free*</i> | - | - |
| Home care is free | 0.37 (0.16 - 0.58) | <0.001 |

* Reference attribute level

All attributes were found to have a strong impact on patient choices. The strongest preferences were for the attributes concerning the focus of palliative care and unpaid caregiver support. **Patients placed the highest value on a service that focused on improving quality of life, with or without extending life, rather than a primary focus on extending life.** They also preferred choice scenarios that described family using their free time to care, or receiving a government allowance to provide care, rather than give up work and receiving no payment. **Overall, patients placed significant value on the process of accessing care and aspects of how services are delivered – dimensions of quality of life not considered or measured using economic evaluation methods.**

Bereaved carers survey

Responses from 767 bereaved carers were used in the analysis: 245 in the U.K., 282 in Ireland and 250 in the U.S. Mean health and social care costs per person were higher in the U.S. and Ireland than the U.K. Variation in total per person costs was wide (e.g., \$6,351 - \$270,989 among US non-cancer patients) and statistically significant. Hospital costs accounted for between 83 and 88% of total costs, followed by community care costs (6-16%). Palliative care costs were lower (1-10%). Stays in intensive care units were the main driver of hospital costs.

Table 2 Mean health and social care costs

| Country | Diagnosis | Hospital costs | Social care | Total costs |
|----------------|------------|----------------|-------------|-------------|
| Ireland | Cancer | \$29,727 | \$5,838 | \$35,565 |
| | Non-cancer | \$25,552 | \$3,629 | \$29,181 |
| United States | Cancer | \$28,497 | \$4,438 | \$32,935 |
| | Non-cancer | \$29,929 | \$4,436 | \$34,365 |
| United Kingdom | Cancer | \$13,276 | \$2,117 | \$15,393 |
| | Non-cancer | \$13,854 | \$2,813 | \$16,667 |

Key findings

Patient surveys

- Patients understand and agree with one of the core objectives of palliative care: to improve quality of life.

- Patients prioritised ease and efficiency of access to services including out-of-hours access and free care at home. They also demonstrated preferences for supports that minimise caregiver burden.
- **The results indicate the process of accessing services and supports may contribute much more substantially to patients' experiences, satisfaction and, quality of life than previously understood.**

Bereaved carers survey

- Patients in the U.K. were more likely to be cared for at lower costs than those in Ireland and U.S.
- Satisfaction with care was highest in palliative care unit/inpatient hospice consistently in all countries.
- **Over 80% of health and social care costs in the last three months of life for older people who receive specialist palliative care are for hospital care. This is consistent across the three countries and cancer and non-cancer.** High costs in this group may reflect the fact that patients were identified through hospital palliative care teams. Moreover, high costs are often a trigger for specialist palliative care consultation.
- Lower costs in the U.K. may provide insights to improving value of care in other countries.

2.3 International Access, Rights and Empowerment Plus (IARE Plus) study

Background

Concerns have been raised that **current approaches in economic evaluation, which focus on health-related quality of life, do not capture the full impact of palliative care interventions or many attributes of care or process valued by patients.** If it is generally accepted that all people should have access to high quality end-of-life care, then **it is important to ensure that resources are focused towards providing those elements of care patients and their loved ones derive the greatest benefit from.** Knowing those attributes of palliative care packages patients and carers value most would provide information to policymakers about how services would best be delivered and identify funding priorities within palliative care. Additionally, variation in palliative care service configuration and delivery within Ireland means it is important to explore potential regional differences in preferences for services and supports near the end of life.

The IARE Plus study set out to explore patients' and informal caregivers' preferences for services and supports when living with a life-limiting illness using a discrete choice experiment (DCE). It examined how these expressed preferences are influenced by participants' characteristics and their experiences with, or perceptions of, specialist palliative care services. It also evaluated the concordance between patients' and caregivers' priorities. Development of this research was influenced by the findings of the IARE study.

Methods

The study was completed in two phases, combining qualitative and quantitative methods. Phase I was a qualitative study focused on identifying and validating the attributes and levels for the DCE instrument. In Phase II, data were collected during face-to-face interviews with patients and caregivers using the DCE, validated instruments, and additional questions focused on their experiences with, and perceptions of, SPC services.

The DCE contained eight attributes related to key priorities and concerns throughout illness, as discussed by patients during qualitative interviews. These attributes comprise: knowing who to contact, cost of care, access to SPC services, symptom burden, hours of assistance required from

informal caregivers, arranging access to services through a key contact, decision making, and place of care. Caregivers were also asked about their financial hardship and the caregiving burden they were experiencing. **Patients and caregivers were asked identical questions in the DCE tool, thus enabling comparison of their preferences and priorities. This information is important in policy planning and evaluation as it may help identify differences in goals and priorities, a key consideration within palliative care as services are usually delivered as a package to both the patient and their loved ones (34).**

To explore the influence of experiences with SPC, participants were recruited purposively across three sites in Ireland with different models of palliative care service provision: the Mid-West, Mayo, and North Dublin. In total, 144 people were interviewed for the study: 69 patients and 75 caregivers.

Results

The results of the DCE with patients and caregivers are shown in Figures 3 and 4, respectively. A positive coefficient for an attribute level suggests that participants preferred it relative to its reference level. Attribute levels with a p-value of less than 0.10 were deemed to have a statistically significant influence on preferences and are indicated in bold.

Overall, the results indicate **that ease of access to services and supports is a key priority for both patients and caregivers. This included knowing whom to contact when they had questions or needed advice, ongoing access to palliative care throughout their illness and having a caseworker or other healthcare professional to provide them with information and help arrange access to services.** In addition, people also reported they would benefit from engagement from healthcare professionals such as making time for communication and providing reassurance and solutions around health or social concerns. **The results are similar to those from the IARE study, which found that the nature of the process of accessing care and support plays a substantial role in determining the quality of peoples' experiences.**

Figure 3 DCE results: Patients

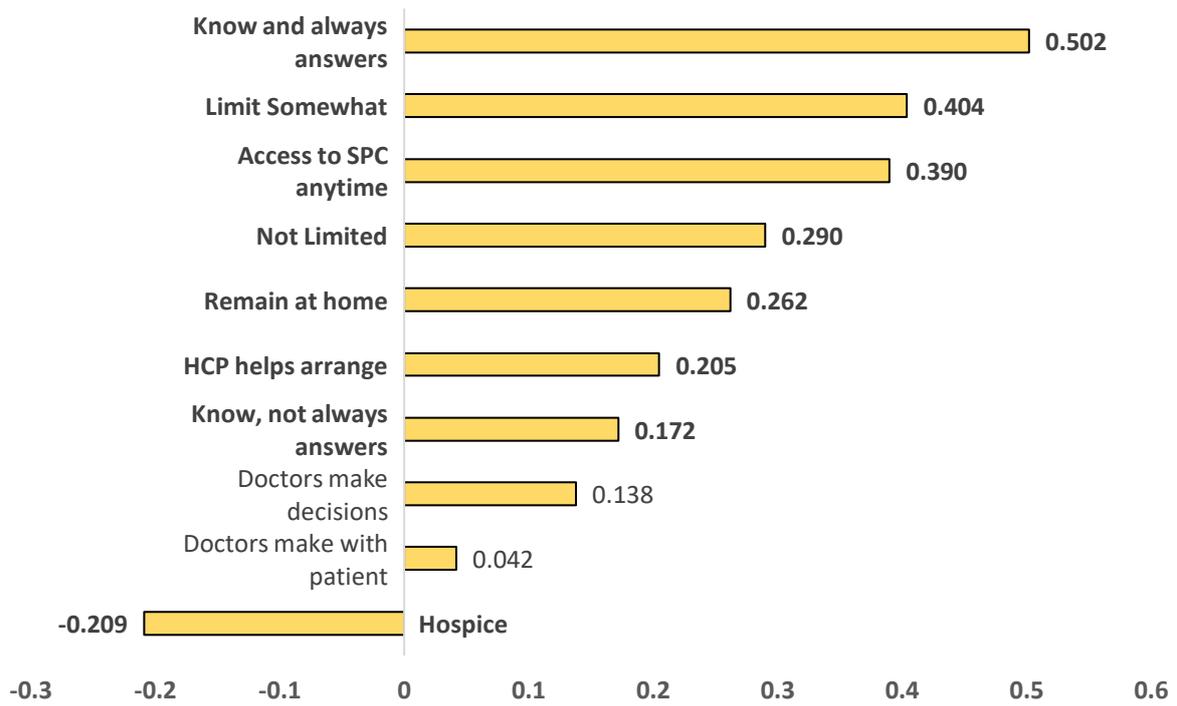
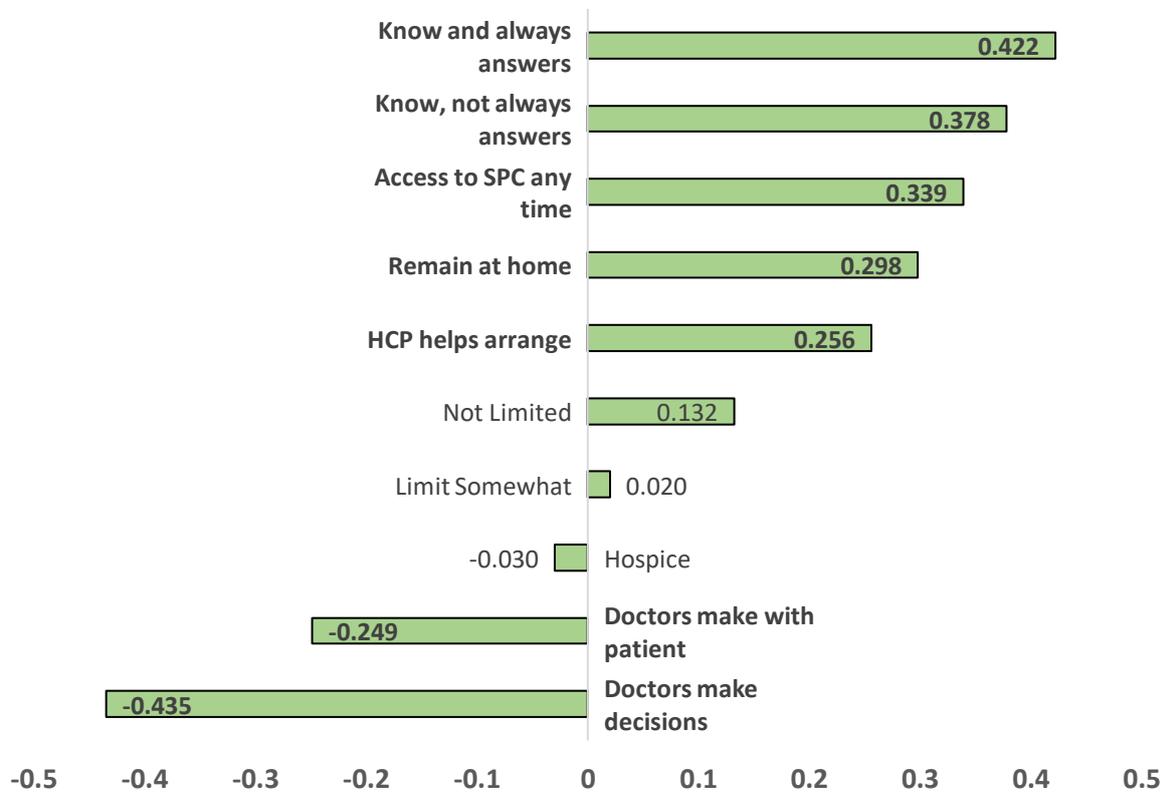


Figure 4 DCE results: Caregivers



Interviews with caregivers also revealed that feelings of financial strain related to caregiving were quite common. A significant proportion (40.6%) agreed that caring for their loved one was causing them to dip into savings meant for other things. Over a third (34.8%) indicated that they could not afford spending on the 'little extras' because of the expense of care, and almost one-quarter (24.6%) reported that they had to give up necessities because of the costs associated with caregiving. And while a sizeable proportion of participants reported experiencing some type of financial challenge related to caregiving, surprisingly few (11.7%) indicated that caring for their loved one was too expensive. Regression analysis suggests that experiencing financial challenges was directly linked with increased caregiver burden in this sample.

Key findings

- Patients and caregivers attribute improvements in their quality of life to ease of access to services and information.
- Similar to the IARE study, **the findings indicate that in difficult times, barriers such as out of pocket costs, delayed or unpredictable access to services and long waiting times for care will increase anxiety, diminish quality of life and undermine satisfaction with the healthcare system.**
- Financial challenges may be a key contributor to caregiver burden.

2.4 Palliative Care for Cancer Study (PC4C)

Background

The PC4C study was funded by the NCI and NINR under the auspices of the National Institutes for Health (NIH) in the United States. This was a four-year prospective cohort study of PCC for adults admitted to five hospitals with an advanced cancer diagnosis. Researchers collected demographic, socioeconomic, and clinical data on eligible people admitted to participating hospital sites and measured key outcomes over the course of the admission: pain and symptom management, patient and caregiver experience, cost of hospital care, and receipt of palliative care.

The principal investigator for this project, Diane Meier, MD and fellow investigator R. Sean Morrison, MD at ISMMS were also senior researchers on the Atlantic -funded IARE project. With financial support from the Health Research Board and NIH, this pre-existing IARE collaboration between ISMMS and TCD was continued in order to incorporate economic analysis of the PC4C data – a partnership that harnessed ISMMS's status as the national leader for palliative care research in the United States with TCD's expertise in economics of palliative and end-of-life care in Ireland.

Methods

Prior to analysis of the original PC4C data, investigators conducted a literature review on prior economic studies of the PCC intervention. This process **identified 10 prior studies with a consistent primary finding: receipt of a palliative care consultation during the hospital admission was associated with lower cost of care.** (37).

However, an important limitation to this body of work was also identified. Prior studies had repeatedly removed a small minority of patients from their samples who had stayed an unusually long time in hospital. This had a number of significant implications (38).

First, published results were at greater risk of bias than previously realised because length of hospital stay is an outcome that treatment can impact. Consequently, defining the analytic sample by length of stay has an endogeneity problem (that is, a key explanatory variable is associated with the outcome of interest). Second, it was not clear if the key conclusions reported by prior studies would have persisted if long-stay outliers had been retained. These results were not necessarily robust. Third,

even in the absence of concerns about bias and robustness, reported results were not maximally useful because length of stay is not known at hospital admission. Even if it were possible to identify reliably that a given treatment is efficacious or cost-effective for adults who stay in hospital n days, this information is not helpful to clinicians or policymakers because we do not know the value of n at admission and the treatment cannot be allocated accordingly. Finally, since decision-makers are most interested in the complex minority who account disproportionately for healthcare spending, treatment-effect estimates for short-stay patients were of limited policy relevance.

The PC4C data were then analysed in this context: what was the impact of PCC on costs for the whole sample, and what was the equivalent estimate for the sample when the longest-stay patients were removed? Researchers found results consistent with prior studies: PCC was associated with lower cost of hospital admission when the 5% of patients who stayed longer than 20 days were removed from the analysis. However, when the 5% of longest stayers were retained no association was observable within the whole sample.

The key questions therefore became: what *baseline* factors are systematically associated with hospital length of stay? And could these be used to identify at admission the circumstances under which PCC was cost-effective? If so then the results would improve economic evidence for policy and practice as well as informing future methods in the field.

Investigators devised two potential hypotheses:

Hypothesis 1 (H1): Timing of palliative care. Longer-stay patients by definition have scope to accrue more days and costs in hospital prior to receiving palliative care, potentially creating a situation where earlier interventions are systematically more cost-effective than later ones, everything else being equal.

Hypothesis 2 (H2): Illness burden of patients. Longer-stay patients are sicker, potentially creating a situation where a complex, long-stay latent class are intractably high-cost with treatment trajectories that cannot be meaningfully altered by different decision-making and advice from PCC (and this complexity cannot be controlled for in analyses).

Results

To investigate H1, the PC4C team altered the definition of “receiving palliative care” according to time from hospital admission. Where prior studies had defined the treatment group as patients who received PCC *at any time*, the investigators instead estimated the effect of PCC on hospital costs where the treatment group was variously defined as receiving PCC within two, six, 10 and 20 days of admission. The results revealed a systematic association:

Table 3 Estimated effect of PCC on cost of hospital admission, where definition of treatment is defined by timing after admission

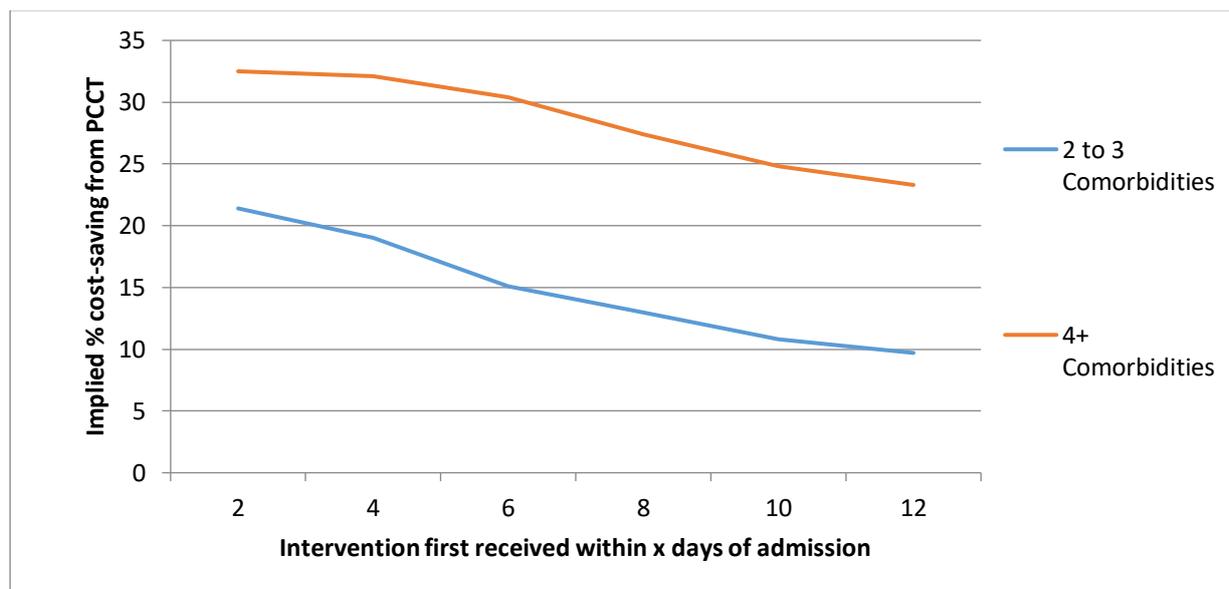
| Treatment defined as within ____ days of hospital admission | UC (n=) | PCC (n=) | All (n=) | Estimated incremental effect (95% CI) | P value | Implied saving |
|--|----------------|-----------------|-----------------|--|-----------------|-----------------------|
| Any time | 734 | 286 | 1020 | -117 (-1780 to +1546) | 0.89 | 1% |
| 20 | 742 | 278 | 1020 | -902 (-2201 to +397) | 0.17 | 10% |
| 10 | 750 | 270 | 1020 | -1062 (-2339 to +214) | 0.10 | 12% |
| 6 | 767 | 253 | 1020 | -1664 (-2939 to -389) | 0.01 | 19% |
| 2 | 811 | 209 | 1020 | -2719 (-3917 to -1521) | <0.01 | 30% |

UC: Usual care only. Estimates derived using propensity scores and generalised linear model with a gamma distribution and a log link. For full results see (39) or contact authors for details. Results are robust to myriad sensitivity analyses, details from authors.

The top row of Table 3 is the same as in **Error! Reference source not found.**: there is no association between PCC at any time during the admission and cost of care. As we move down the table, later consults are excluded from the treatment group and the estimated cost-saving effect grows. **Early PCC, within two days of admission, is associated with a large and statistically significant cost-saving effect.**

To investigate H2, the PC4C team defined sub-samples by number of comorbidities (i.e., serious co-existing conditions)– 2 to 3 comorbidities, or 4+ comorbidities (40) – and estimated effect for PCC according to timing following admission:

Figure 5 Estimated effect of PCC on cost of hospital admission, where definition of treatment is defined by timing after admission and samples are defined by number of comorbidities



Copyrighted and published by Project HOPE/Health Affairs as (41). The published article is archived and available online at www.healthaffairs.org/. Implied saving is calculated as (Estimated incremental effect/Mean cost for UC patients). See (41) or contact authors for details. Results are robust to myriad sensitivity analyses, details from authors.

The results in Figure 5 show a clear pattern: palliative care consultation within 10 days of hospital admission is associated with lower cost of hospital care for patients with multimorbidity, and this cost-saving effect is larger for more complex patients. These results are robust to the time-to-consult association: **for any given sample defined by complexity, earlier treatment has a greater effect; for any given definition of the intervention according to timing, the effect is largest for the most complex patients.**

Key findings

H1 was supported by the results: earlier consultations are associated with a larger cost-saving effect.

In theory, this result might be traced to unobserved factors that are associated with treatment timing and costs but not under investigator control. However, follow-up analyses have shown that longer-stay patients by definition have scope to accrue more days and costs in hospital prior to receiving palliative care, creating a situation where earlier interventions are systematically more cost-effective than later ones, everything else being equal (42, 43). Papers have also shown that cost-savings accrue through a combination of reduced length of stay and reduced futile/high-intensity care (43), and that incorporating intervention timing is essential to accurate estimation of PCC impact on costs (42). Precisely how 'early' a consultation has to be following admission to reduce costs significantly is methodologically complex and has not yet been definitively identified.

H2 was not supported by the results: patients with a higher illness burden were not associated with a lower cost-saving effect. Indeed, the reverse was true. Palliative care's estimated impact on costs was larger for patients with higher numbers of comorbidities (41). This was the first time that this result had been reported, identified only following the re-specification of the treatment variable to incorporate timing. A subsequent analysis showed that comorbidities and complications are the key drivers of hospital utilisation in this sample, and so **the increased effect of PCC for those sicker patients represents a key dynamic to improving cost-effectiveness of services to this high-priority population (44).**

Additionally, the findings of the literature review (37), methodological critique of the field (38), and new methods developed to incorporate intervention timing (39) have set a new standard in economic evaluation of in-hospital PCC.

3. Policy Implications of this New Evidence

There has been limited evidence available to aid in the development of models of palliative care provision or to assist in making decisions about which elements and characteristics of palliative care service provision should be prioritised. This report has summarised findings from four recent, innovative economic studies of palliative care. Three of the studies were funded by Atlantic; the fourth was funded by the NCI and NINR in the US and conducted its economic analyses through an Atlantic-supported research collaboration.

Key findings and policy implications from these studies are as follows:

- **Palliative care policy should be based on evidence of patient preferences rather than the decisions of proxies (IARE/IARE Plus). People living with serious illness have strong preferences for elements of experience not captured when using tools that focus exclusively on health-related quality of life.** For example, patients appeared to derive benefit simply from knowing they would have barrier-free access to services. This included having direct contact with engaged and supportive healthcare professionals and knowing whom to contact

when they needed advice. They were also clearly concerned about the impact their illness or care needs may have on informal caregivers.

- **People accessing palliative care often receive significant support from family and informal caregivers, which all have a cost implication for society (IARE/IARE Plus/EEPCI).** However, because it can be challenging to record and value these inputs to care they are often overlooked in costing studies in palliative care. **Failure to take all relevant costs into account may result in preference being given to interventions or models of care that shift a larger proportion of costs onto patients and caregivers.** Additionally, higher formal care costs do not seem to lower informal care costs, suggesting they may act as complements, rather than substitutes. Instead of being replaced in their role by increased access to formal care services, informal caregivers may find themselves free to shift their focus towards supporting the wider needs of their loved one.

The magnitude of informal care to people at end of life poses challenges in understanding cost and quality of care received (IARE/IARE Plus/EEPCI). Long-term policy considerations must include potential payment mechanisms to reward informal care and reduce unnecessary formal health care utilisation, but also target people who live alone or in isolation, who cannot avail of informal care, and may be underserved and at greater risk of adverse outcomes as a consequence.

- **Timely palliative care following hospital admission for adults with advanced cancer is associated with lower cost of care, and this association is stronger when the intervention is provided earlier in the admission (PC4C).** There is no evidence that these savings are correlated to worse outcomes. Indeed, they accrue through earlier hospital discharge (consistent with patient preferences) and reduced tests and imaging.

However, **shorter LOS arising from hospital palliative care must be matched by appropriate post-discharge services to ensure that savings made in the hospital are not simply passed on to the patient and their family.**

- **The cost-effectiveness of hospital palliative care appears to be greater for adults with higher illness burden (PC4C).** This appears to result from palliative care addressing complex needs and decision-making, e.g., polypharmacy for multimorbid patients, better than single-disease-focused clinical teams. Clinicians and policymakers ought to develop ways to identify populations for whom the benefit is greatest at baseline and target interventions accordingly.

For both patients who receive palliative care and those who do not, illness burden is a consistent driver of utilisation during hospitalisation (PC4C). **In a context where a small number of patients with complex needs account for disproportionate levels of healthcare costs, palliative care may be a more effective tool than previously realised in curbing future cost growth.**

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