Report paints comprehensive picture of palliative care services in Ireland

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A new report into the availability, variety, quality, cost, effectiveness and use of specialist palliative care services in three regions in Ireland has just been published by researchers from Trinity College Dublin and the Economic and Social Research Institute (ESRI).

The research team led by Professor Charles Normand, Edward Kennedy Professor of Health Policy and Management at Trinity found a picture of varying levels and kinds of palliative care services, similar costs despite these differences and high overall satisfaction levels among individuals and their carers with the services offered, although inpatient hospital care for people receiving palliative care was not as highly rated. It also found varied access to care and a picture of older people as the key carers of other older adults.

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering through early identification, assessment and treatment of pain and addressing physical, psychosocial and spiritual needs.

The key findings were:

1. The researchers found wide variations in the availability of specialist palliative care services (SPC) between the three regions. Not all areas have access to Specialist Palliative Care (SPC) in-patient units, specialist day care centres, outpatient

clinics attached to SPC units or hospice care. Availability of services also varied from 24 hours a day, seven days a week to office hours only with further variations in availability of multidisciplinary teams, home help and public nursing capacity.

2. Most individuals and their carers reported that getting access to community SPC or hospice care (where it was available) was fairly easy or very easy while those attempting to access a bed in a hospital when required found this much more difficult, particularly in the Mid West and Midlands, with almost 40% and 35% of carers reporting this access to be 'fairly difficult' or 'very difficult'.
3. In each area people were most satisfied with the quality of care received from community SPC teams, despite the diversity of how these services are delivered. The report found that the quality of in-patient hospital care was lower, particularly in terms of emotional support for families, with researchers noting this may reflect both underlying problems in the experience of hospital care and a more general perception of the inappropriateness of the acute hospital setting for people nearing the end of life. In addition, in the Mid West, the only area where both in-patient hospice and in-patient hospital services were available, the hospice scored much higher than hospital care on every quality measure. In the other areas, respondents only had experience of one kind of in patient service and rated quality levels without the ability to compare it to hospice care.
4. The research presents a picture of older people as the primary informal carers of those who are unwell, except in the South East where adult children provided the largest proportion of care. When the spouse/partner is the main informal carer they normally provide more than 60% of the informal care, with adult children playing an important but smaller role. The majority of all carers in all areas were women aged 35-64.
5. An important objective in many cases is for the patient to die in

an appropriate and/or their preferred location. A patient's preferred place of death 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 their recognition of this and wish not to place this burden on family. Overall, almost 75% of individuals died in the place they or their carer believed they preferred to die in during the last week of life. Individuals were more likely to die in their preferred place where there was a more developed service available and of note was that in the Mid West where in-patient hospice care is available, more individuals died in this setting.

6. The cost of palliative care in each region was quite similar despite the considerable variations in the kinds of services being offered. The average total costs of formal care in the person's last year of life ranged from just over €40k (South East) to just over €50k (Midlands and Mid West).

Speaking about the significance of the findings, Professor Charles Normand, Edward Kennedy Professor of Health Policy and Management at Trinity, said:

"It is interesting to note how much care of older dying people is provided by other older people, especially spouses and partners. We need to think of older people as a resource and as providers of services as well as people who need care. It is also important to understand that the provision of formal care does not lighten the load of informal carers, but does allow them to use their time to address the wider needs of their relative."

"Evidence from this study shows that more developed palliative care reduces the costs 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. "

"There is evidence that people put great value on the palliative care they receive, and in particular appreciate getting speedy access to care at a time of great stress. Especially where inpatient hospice is available it is possible substantially to reduce the numbers who die in hospital or have hospital admissions close to the time of death."

"It has long been recognised that palliative care is not only end of life care. Where services are more developed this allows earlier referral for specialised support, and the skills of palliative care can be provided over a longer period. Where services are less well developed they are only generally able to address needs nearer to the end of life. "

The research looked at cost and effectiveness of alternative models of specialist palliative care in the HSE Midlands Area (Laois, Offaly, Longford, and Westmeath), the HSE Mid West area (Clare, Limerick and North Tipperary), and the HSE South East area (South Tipperary, Waterford and Wexford but excluding Carlow/Kilkenny).

Types and availability of Palliative Care Services in Ireland:

- There are eight dedicated SPC In-Patient Units in Ireland with nine local health areas having no such unit and no access to specialist in-patient beds. Staffing levels vary in In-patient Units and access to services can also be delayed as waiting lists exist for admission to some units.
- Specialist Palliative Day Care Centres and outpatients clinics attached to SPC units provide access to specialist care, change of environment for patients and respite for families and carers. There are six such units, the majority of which operate Mon-Fri, 9-5pm with wide intra regional variation in the availability of

such services. The nine areas with no in patients units also have no specialist palliative day care centres.

- Community SPC teams or home care teams provide specialist support and advice to patients, families and community-based professionals. The vast majority of these services are consultant-led, multidisciplinary services but in some areas they continue to be nurse-led services. However, many community SPC teams do not comprise the full complement of staff for a multidisciplinary team so in some situations it becomes more difficult to maintain patient care in the community, resulting in admission to in-patient facilities. Overall, GPs and Public Health Nurses are the main providers of general palliative care in the community setting.
- SPC Services in General Acute Hospitals involve SPC teams who support and collaborate with other hospital teams, as is the case with teams in the community. Patients receiving SPC hospital team care usually remain on their own wards under the care of their referring consultant. Approximately 38 of the acute general hospitals in Ireland have access to dedicated SPC teams.
- Hospice Care - The voluntary sector makes significant contributions to the provision of palliative care services in Ireland, across all aspects of service provision including in-patient, day care, outpatient and community SPC services.

More information: The full report is available online: www.medicine.tcd.ie/health_pol … report-July-2015.pdf

Provided by Trinity College Dublin

palliative-ireland.html