Death and dying in Wales

An analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life

Executive summary

1. Approximately 32,000 people die in Wales each year. It is estimated that 75% (24,000) will need some form of palliative care. Palliative care is the holistic care of patients with advanced progressive illness. It includes management of pain and symptoms and provision of psychological, social and spiritual support. The goal of palliative care is to achieve the best quality of life for patients and their families, rather than curing the illness. Specialist palliative care – delivered by clinical specialists - is appropriate for people with more complex conditions.

2. In partnership with the Bevan Foundation, Marie Curie has undertaken an analysis of data on deaths in Wales in 2012 provided by the NHS Wales Informatics Service (NWIS) in order to explore hospital activity of people in the final year of life and assess where variance in access exists in relation to receipt of specialist palliative care.

3. The data confirms that people in their final year of life make heavy use of hospital services, averaging 2.13 admissions and 33.9 bed days. In total people in the last 12 months of life accounted for more than 1 million NHS bed days in 2012, nearly a quarter of all NHS bed days. Although variations by cancer diagnosis exist, people who died from cancer typically experience a higher number of admissions but a lower number of bed days. Conversely, people who died from dementia have a much lower number of admissions but spend a significant amount of their final year (52.3 days) in a hospital bed.

4. Overall, only 17% of those who died in 2012 received specialist palliative care. This is less than a quarter of the level of estimated palliative care need. Receipt also varies significantly with underlying cause of death. Whilst almost half of people who died from cancer received specialist palliative care, only 5% of those with other diagnoses are recorded as having received this care. Older people who died from cancer were found to be less likely to have received specialist palliative care than younger people, and significant variations exist between different cancer diagnoses.

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5. Although other studies suggested that there would be a negative correlation between access to palliative care and levels of social deprivation, this was not evident in the data. This could mean that Wales has an important story to tell around equality of access in relation to deprivation. However, significant variations in average numbers of admissions, bed days and receipt of palliative care by health board suggest that inequalities do exist across Wales depending upon where a person lives and where they are cared for.

6. On the basis of the data available, the authors have make the following recommendations:

   i. We call on the Welsh Government and NHS Wales to focus effort on reducing the number of emergency bed days spent by people in their last year of life. We feel that a 10% reduction over a three year period is a reasonable target. This is the equivalent of 188 hospital beds.

   ii. We would urge the Welsh Government and NHS Wales to commission a study to establish whether equity of access to palliative care across socio economic groups is the case or whether the current data is hiding the reality.

   iii. We call on Public Health Wales to work with NHS Wales and independent sector providers to explore the feasibility of bringing individual level palliative care data into one national data set that captures activity and outcomes from hospices and specialist palliative care services, including information on demographic details, activity information and patient outcomes.

   iv. We urge the Welsh Government and NHS Wales to focus on those areas where there appears to be insufficient access to specialist palliative care services:
      a. For those with a non-cancer diagnosis
      b. For older people, in particular those with terminal cancer

   v. We think that work is needed to establish what is behind the apparent inconsistencies of provision across health boards. It is important to establish whether this is an issue of how services are being coded, whether there are specific barriers to access, variations of provision or some other factors.