

These comments are directed to section 3: End-of-Life Care and in particular to factual material presented in Box 3.1 (page 97) and figure 3.2 (Page 98).

General comment

The End-of-Life (EoL) review and recommendations are of a high quality and the recommendations, if implemented would have the **triple effects** of:

- Improving the quality of EoL care for Australians, especially those with terminal conditions other than cancers.
- Particularly address the unmet needs of the very large numbers who die as residents of aged care facilities
- Create very substantial cost savings through
 - (a) substitution of care in the community or in residential aged care for admitted care in acute hospitals
 - (b) reducing rates of expensive (often futile or distressing) medical and surgical services in hospitals during terminal-phase illness. (1)

Specific comment: Place of death (pp 96-98)

- 1. There is currently no accurate information on place of death in Australia.**
- 2. There are no population-based data describing preferences of Australians for a “place of death”, especially for the relevant population, which would be limited to the frail-elderly (?definition) and those in defined End-of-Life situations.**
- 3. The use of presumed data on place of death as a measure of satisfactory delivery of Palliative or other EoL service is naïve and inappropriate.**

The material in pages 96-98 of the Report (including Box 3.1 and Figure 3.2) contain **errors of fact and questionable interpretations of existing data sources.**

Comment re stated preference for “dying at home”.

A crude response rate of 70 per cent was found in the PCA survey and also in an earlier survey in South Australia (3). **However both of these studies surveyed healthy persons as young as age 16, a sample for whom considerations of dying or place of death are known to be unrealistic.** The SA study makes specific comment on the **selection bias** in their survey and report that, for persons in the demographic of cancer patients, **58 per cent** cited a preference for “home death”. They found that younger and healthier persons opted for home death, while older, better educated persons with some awareness of EoL issues, including ACDs were more likely to nominate hospices.

In 2008 another Australian study (4) demonstrated that preference for both place of

care and place of death changed for about one-third of both sick persons and their carers as the illness progressed towards death. When death was near the proportion continuing to prefer to die at home was **35 per cent, and rates as low as 30 per cent** have been reported in overseas studies (5).

Place of actual death is a very crude measure of the extent to which palliative care meets the needs and preferences of its clients. The purpose and aim of Palliative services is certainly to maintain comfort and function (quality of life) in the preferred location for as long as possible, and to minimise unwanted hospitalisation. The terminal events of a chronic progressive illness however, often dictate that care at home is no longer practical or safe. It is the duration and quality of **pre-terminal care** which is important, rather than the “final act”. Recent data from community-dwelling patients in Europe showed that, while 45 per cent died at home, 73 per cent died in the setting of their last stated preference (6).

These authors state: “Looking at whether patients die at their preferred place may therefore do more justice to the diversity of characteristics and preferences of patients. Some authors have therefore stated that ensuring death occurs in the preferred place is a more appropriate reflection of the quality than the proportion of home deaths [2], [10], [23]–[25]. Their main criticisms of home deaths as a quality indicator are that this implies a home death is optimal for the patients whereas it is not always realistic [5], [8], [10], [15], [17], [22], [26]–[29], due to the high burden on informal caregivers, the inadequate quality and quantity of resources in the home situation and the unrelieved suffering.” (6)

The writer would add, from 18 years of Palliative care experience, that mounting needs for symptom control, increasing physical dependency, resultant carer distress or unexpected acute medical events not uncommonly occur in patients who are approaching death. These often overwhelm the capacity of families and community-based care providers. Hospital (or preferably hospice) is often a welcome haven for patient and carers in such situations.

The principal point is that it is naive to cite rates of “Home death” as the principal criterion by which to assess efficacy of palliative care or EoL care generally. Where they are quoted there should be due regard for the sources, contexts and inherent statistical biases of the data collections.

2. “Fourteen per cent (of Australians) die at home”.

This calculation is based on the residual population of deaths after subtracting known deaths in hospitals and reported deaths from residential aged care. The citation in Box 3.1(P97), apart from being 12 years old, claims that the value is too high due to deaths in ED not being included in the “hospital deaths”. More recent hospital data would appear to have corrected this.

There is however another source of inaccuracy in “place of death” estimations

which involves the large percentage of people who die as aged care residents.

When a resident is transferred to hospital for any reason, it is customary to retain the care place in the resident's name for a statutory period. Should the resident die in hospital, the separation from aged care is frequently adjusted from “hospital leave” to “death”. The person is therefore shown as dying in two sets of institutional data, even though there is of course only one death certificate.

The exact dimension of transfers of RAC residents who then die in hospital is not known, nor is the exact proportion of those recorded as dying in two locations. Data from the Department of Veterans' Affairs databases suggest that for persons aged over 70 years, approximately one-quarter of all hospital deaths involve recent transfers from aged care (1). Only one national study, from 2009, has examined transfers between hospitals and RAC which identified almost 10000 deaths in hospital among these transferees(2). The current numbers are likely to be higher.

A further consideration must be that, with approximately 40 per cent of Australians now dying as Aged care residents, and the great majority of these dying “in place”, a much lesser number/ proportion of deaths form the potential pool for deaths in private homes. Even should the quoted figure of “14 per cent” apply, this could equate to up to $(14 \times 10/6) = 23$ per cent of the deaths which potentially occur in private homes.

3. “80000 deaths occur in hospitals”.

The proportion of all deaths which occur in admitted hospital patients has been steadily falling in the past decade from almost 52 per cent to 49 per cent (AIHW, Australian hospital statistics). In 2014-15 total hospital deaths were approximately 76500. Of these just over 43000 were in acute care services, while **more than 28000 (35 per cent of total) were in dedicated palliative care services.** The absolute numbers and proportions of these patients are also increasing. Hospital patients and hospital deaths are not homogeneous.

In addition it is probable, based again on DVA data (1), that at least 25 per cent of all patients who die in acute hospital units receive some form of palliative care.

It would appear therefore that of 159000 Australians who died in 2014-15 (ABS) approximately $(43000 \times \frac{3}{4}) = 32000$ (just over 20 per cent) died in an acute hospital service with no recognition of or access to palliative care. It is possible, based upon the considerations of sections 1 and 2 above, that an equal or even greater number died in their own homes, many with the support of community palliative care services.

It is also noted that where palliative care is available during terminal hospital episodes, there are substantial reductions in high-technology interventions and in hospital costs (1).

The above statistical considerations are commended to the Commission. The EOL section contains many highly desirable recommendations which could do much to improve the care of persons, both patients and carers, who are facing death. It would

be unfortunate if such a high level document continued to promote information which is inaccurate and misleading.

Recommendations

- 1. That existing data sources in government purview be analysed to more accurately define the nature of EoL care with reference to place of death and provision of palliative care services.**
- 2. That given the high proportion of deaths in Aged Care, and the likely disturbances and costs of frequent transfers into hospitals, that priority be given to systematic palliative care services in Residential Aged Care Facilities.**
- 3. That specialised palliative care services be an embedded element of all acute care hospitals.**

References

- (1) Ireland A W. Access to palliative care services during a terminal hospital episode reduces intervention rates and hospital costs: a databases study of 19707 elderly patients dying in hospital, 2011-2015. *Intern Med J* 2017; 47 (5): 549-556
- (2) Australian Institute of Health and Welfare 2013. Movement between hospital and residential aged care 2008-09. Datalinkage series no.16.CSI 16. Canberra: AIHW
- (3) Foreman LM, Hunt RW et al. Factors predictive of preferred place of death in the general population of South Australia, *Palliative Med* 2006; 20 (4)
- (4) Agar M, Currow D et al. Preference for place of care and place of death: are these the same questions? *Palliative Med* 2008; 22 (5).
- (5) Billingham MJ, Billingham SJ. Congruence between preference and actual place of death according to the presence of malignant or non-malignant disease: a systematic review and meta-analysis. *BMJ Supportive and Palliative Care* 2013; 3:144-152
- (6). De Roo ML, Missinesi C et al. Actual and preferred place of death of home-dwelling patients in four European countries: making sense of quality indicators. *PLOSone* 2014; <https://doi.org/10.1371/journal.pone.0093762>

Anthony W Ireland MBBS PhD FRACP FChPM
Palliative Medicine Physician (retired)

Honorary Clinical Senior Lecturer
School of Public Health
University of Sydney.