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Factors affecting place of death in Western Australia

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Abstract

Despite the growing international interest in place of death and its relationship to healthcare policy, virtually nothing is known about where people die in Australia. To address this gap our study employs a longitudinal, population-based retrospective cohort study of people who died in Western Australia over a 30-month period. Mortality, morbidity and palliative care service data sets from the Western Australian Data Linkage System were examined to provide demographic and disease-specific characteristics and healthcare service use in the last year of life for the 26 882 people who died during this time. The main outcome variables of the study were accommodation setting at the time of death (usual place of residence, hospital, hospice, residential aged care facility and other) and specialist palliative care use (hospital, home-based, both or neither). Over half of Western Australians died in hospital, but as people age there is an increasing tendency to die in their usual place of residence, which may be a private residence or an aged care facility. People who accessed community-based specialist palliative care had a seven times higher chance of dying in their usual place of residence. Importantly, this information is provided, not just for cancer deaths, as has been the practice to date, but for a range of other painful and life-limiting conditions considered amenable to palliative care. The unique population data on palliative care service use, made possible by the data linkage system, provides a basis for planning health services and policies.

Keywords: Palliative care; Place of death; Cancer; Non-cancer conditions; Population-based

Introduction

Where people die is of importance, not just because individual choice is highly valued in contemporary society, but also for the purpose of healthcare planning. With escalating medical costs associated with the last year of life, and often the last weeks of life (Lubitz et al., 2003) helping people to remain in their homes to die may achieve the two outcomes of cost containment and patient choice. A number of studies have focussed upon preferences for place of death and, to a lesser extent, the provision of population-based data for place of death for people dying of cancer. However, very few studies provide broad demographics and service use data for large populations and none have provided even minimal Australian data for the last 10 years, a gap our study seeks to address.

When asked where they would prefer to die, the majority of people express a wish to die at home (Hays et al., 2001; Tang and McCorkle, 2003; Tiernan et al., 2002) though a recent study has also shown a stronger than anticipated preference for a hospice death (Thomas et al., 2004). The experience

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of caring for family members at home has also been noted as more positive for both families and patients, though this is dependent on the provision of supportive home-centred care (Catalán-Fernández et al., 1991). Despite these preferences only one-half of patients achieve their wish to die in a place of their choice (Ashby and Wakefield, 1993; Carroll, 1998; Tiernan et al., 2002) and most patients die away from home (Tang and McCorkle, 2001).

Place of death is related to, and affected by, various demographic factors. Children are more likely to die at home than adults. In the United Kingdom (UK), Higginson and Thompson (2003) found that 52% of children aged 0–15 years with cancer died at home, whereas 30% of those aged 16–24 years died at home. In adults, the evidence on age and gender varies with both women and older people less likely to die at home in the UK (Gatrell et al., 2003; Higginson et al., 1998) but more likely to die at home in Italy (Constantini et al., 2000; De Conno et al., 1996) and Canada (Burge et al., 2003). Patients are also more likely to die at home than in hospital if they are not single (Constantini et al., 2000; De Conno et al., 1996) and live outside of an urban centre or in a rural area (Burge et al., 2003; Catalán-Fernández et al., 1991). Condition-specific factors also influence place of death. In an Australian study of patients who died of acute myeloid leukemia, none died at home (Maddocks et al., 1994). Other studies have found that patients with cancer are less likely to die at home if they have malignancies of the lymphatic or haematological system (Bruera et al., 2003; Higginson et al., 1998). Population data from the UK in 1994 indicated that 27% of deaths from cancer occurred at home and that this figure had changed very little over the previous 10 years (Higginson et al., 1998). This appears to be an international trend with various studies over the past 15 years of patients with cancer illustrating that the minority of patients die at home (Table 1). There is a paucity of data to provide an Australian comparison, though South Australian figures from a population-based study are among the lowest at 18% in 1990 and 20% in 1993 (Hunt and McCaul, 1998).

A comprehensive review of literature published in 1998 found that many people who wish to die at home are unable to do so (Carroll, 1998). The kinds of health services available are likely to influence this outcome; where palliative care is available, in the form of hospice and/or homecare services, patients are more likely to die at home than in hospital. Hunt and McCaul (1998) found that Australian patients with cancer who died at home had higher levels of hospice care (59% in 1990 and 73% in 1993) than those who died in hospitals and nursing homes (41% in 1990 and 50% in 1993). A United States of America (US) study found that hospice patients were more likely to die at home than non-hospice patients, especially when they received home-based care (Moinpour and Polissar, 1989). Supportive professional healthcare within the home is associated with a greater likelihood of dying at home elsewhere as well. Reports of homecare programs for patients with cancer in Italy, Taiwan and Japan show generally higher proportions of patients dying at home (86%, 69% and 43%, respectively) than is usual for this population (De Conno et al., 1996; Fukui et al., 2003; Tang, 2002). Patients who die at home tend to have more home visits from a palliative care team than those who died in hospital (McWhinney et al., 1995) and patients with cancer who die where they wish make greater use of homecare services than patients who do not die where they wish (Tang and McCorkle, 2003).

The studies reviewed here have two limitations. First, almost all the studies were restricted to patients with cancer and provided no information about people who died from other causes. Second, many of the studies generalized the results from samples to the population although regional differences have been identified (Constantini et al., 2000; Higginson et al., 1998) and make such generalizations tenuous. Our study overcame these two limitations by including people who died from a range of causes and by using the whole of population data. This approach was enabled by using the Western Australian (WA) Data Linkage System, which links together data over a period of 20 years from a variety of health administrative data sets, and relates these to individual people (Holman et al., 1999). Studies supported by the WA Record Linkage System are more cost effective compared with studies that require primary data collection and data entry (Brameld et al., 1999). Our study uses Mortality and Hospital Morbidity data sets as well as service use data supplied by Silver Chain Nursing Association, the agency that provides at least 90% of community-based palliative care in Western Australia, a state of Australia which in 2001 had a population of 1 831 998 people (Australian Bureau of Statistics, 2003). By describing the demographics of all Western Australian