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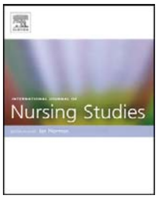

Review

Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence

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ABSTRACT

Background: Hospice care supports patients and their families physically and emotionally through the dying phase. In many countries a substantial portion of specialised end-of-life care is provided through hospices. Such care has developed outside of general healthcare and is commonly provided in a patient's home or in dedicated facilities. Hospice provision may need to increase in the future due to an ageing population with a greater need for access to end-of-life care.

Objectives: In this systematic review we sought to identify the current evidence on (1) the effectiveness, including cost-effectiveness, of hospices, and hospice care in a patient's home and in nursing homes and (2) the experiences of those who use and of those who provide such services.

Methods: We included quantitative and qualitative studies on hospice care that was provided in a patient's home, nursing home or hospice. We did not include studies on end-of-life care that was provided as part of general healthcare provision, such as by general practitioners in primary care, community nurses or within general hospitals. For quantitative evaluations we included only those that compared hospice care with usual generalist healthcare.

The databases CINAHL, MEDLINE, EMBASE, and The Cochrane Library were searched from 2003 to 2009. Evidence was assessed for quality and data extractions double-checked. For quantitative studies we present the outcome data comparing hospice versus usual care. For qualitative evaluations we organise findings thematically.

Findings: Eighteen comparative evaluations and four thematic papers were identified. Quantitative evidence, mostly of limited quality in design, showed that hospice care at home reduced general health care use and increased family and patient satisfaction with care. Main themes in the qualitative literature revealed that home hospice services support families to sustain patient care at home and hospice day care services generate for the patient a renewed sense of meaning and purpose.

Conclusions: Although studies had methodological limitations, in this review we found much evidence to support the benefits of hospice care. There were limited evaluations found on the impact of hospice care on psychological well-being, such as symptoms of depression, and on inpatient hospice care and non-hospital related costs.

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What is already known about the topic?

- The demand for specialised end-of-life care is increasing.
- In many countries a substantial proportion of specialised end-of-life care is provided through hospices.

What this paper adds

- Although mostly from studies with methodological limitations there is consistent evidence that hospice care reduces uptake of provision of secondary care in hospitals and increases patient and family satisfaction with care.
- Qualitative thematic evidence revealed that hospice day care services generate a renewed meaning and purpose for the patient, and that home hospice services support families to sustain patient care at home.
- Few evaluations have been undertaken on inpatient hospice care or on non-hospital related costs.

1. Introduction

Palliative care at the end of life aims to improve the quality of life of patients with a life-limiting illness and their families through the prevention and relief of suffering by early treatment of pain and other physical, psychosocial and spiritual problems (WHO, 2009).

International terminology on hospice care is complex. Whilst there is no universal definition (Radbruch et al., 2009) most would agree that hospice care is palliative and specialist, provided at the end of life and that it has, in general, distinct characteristics (see, for instance, Help the Hospices, 2010; The Federal Medicare Agency, 2000; WHO, 2002). Specifically, hospice care has developed separately and apart from statutory and generalist healthcare services. In many countries it remains separate, although there has been some integration of hospice services within some government regulated health care systems such as in the UK (van Reuler, 2010). Hospice care is commonly location specific; it is either delivered in dedicated freestanding facilities or in a patient's home, although in some countries it has expanded to support to terminally ill residents in nursing homes or other community facilities. However, in some countries specific end-of-life care that is provided in hospitals may also be termed hospice care (for example in the US) while in others, such as the UK, such care is described as palliative but not hospice care (Help the Hospices, 2010). Hospice care can also be characterised by its professional providers, who are often a team that is specialised, dedicated and multidisciplinary. Teams primarily consist of nurses and care assistants as well as doctors, physiotherapists, occupational therapists, dieticians, complementary therapists, chaplains and/or other religious or spiritual representatives, social workers and volunteers (National Care Standards, 2005). Moreover, it is generally agreed that end-of-life care provided by generalist community healthcare staff, such as family practitioners or community nurses, is not hospice care. Hospice care can also be characterised by its features of care, being sometimes described as a philosophy or a model of compassionate care for people facing a life-limiting illness (National Hospice and Palliative Care Organisation, 2009). Hospice care can be described as holistic as it not only supports patients and their families specifically in medical care and symptom management, but also aims to support them emotionally, and spiritually, and provides advice and future planning such as advance care planning. Conventionally, hospice care focuses only on the final stages of a terminal disease (National Hospice and Palliative Care Organisation, 2010).

Countries vary in their provision of end-of-life care. In some almost no formal services are available, in others provision is mostly hospital based (Rocafort and Centeno, 2008). In some countries, both developed (including in Europe) and developing, a substantial proportion of end-of-life care is provided by independent hospice services (Wright et al., 2008). In the UK, where such services are well established, there are 2600 inpatient hospice beds and it is estimated that hospices support over 112,000 people in the community in 1-year (Data for 2006–2007, National Audit Office, 2008). The majority (over 80%) of UK hospice facilities are provided by 189 independent charities (Ward, 2006). The charity Marie Curie Cancer Care is the largest UK provider of hospice care and estimates that it provides nursing care to around 50% of cancer patients who die at home (Marie Curie Cancer Care, 2008). In the US hospice provision is funded by Medicare and private insurance plans but provided by freestanding hospice organisations (both non-profit and for profit) as well as managed care organisations. It is estimated that in 2008 1.45 million US patients and 38.5% of the patients that died that year received services from a hospice of whom the vast majority received the service in their home (National Hospice and Palliative Care Organisation, 2009).

Demand for hospice services may increase due to recognition of the need at the international (WHO, 2004) and the national level to increase access to specialised end-of-life care (see for instance, the Australian Government's National Palliative Care Program, 2000 and the Indian Government's National Cancer Control Programme, 2009) and the global ageing population. Also in countries with developed healthcare services people are living longer at an advanced stage of a terminal illness.

There are systematic reviews that have explored broadly the effects of specialised end-of-life care (Garcia-Perez et al., 2009; Gysels and Higginson, 2004; Zimmermann et al., 2008) but they have not focused specifically on hospice type care including effectiveness evidence with regard to costs.

2. Objectives

The objectives of this systematic review were to identify the current evidence on (1) the effectiveness, including cost-effectiveness, of hospice care in hospices, in a patient's home and in nursing homes and (2) the experiences of those who use and those who provide such services.

3. Method

The review included (1) quantitative analyses comparing hospice care with usual care, and (2) qualitative thematic evaluations of patient, family and health professionals' perspectives on hospice services.