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Review

Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence

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ABSTRACT

Context: Despite the extent of volunteers' contribution to palliative care, and their role in direct patient care, there has been no systematic evaluation of the evidence-base on volunteers in relation to patient and family wellbeing.
Objective: To critically review research, on the impact of volunteers involved in the direct care of palliative patients and their families.
Methods: We searched for studies, reporting patient and family data on the impact of volunteer services in palliative care in thirteen citation databases up to May 2013. We included quantitative comparative studies. We also noted any non-comparative studies, enabling us to give a comprehensive review of the existing research. We also included qualitative studies that explored the experiences of patients and families who received volunteer support, potentially illustrating which aspects of volunteer activities patients and families value. We applied quality appraisal criteria to all studies meeting inclusion criteria. Two researchers undertook key review processes.
Results: We found eight studies. Only two studies were undertaken outside of North America; one in the Netherlands and the other in Uganda. All studies were in adult palliative care services. All evaluated volunteers were in home care settings, three of the studies included other settings such as hospitals and nursing homes. All of the studies fulfilled our quality appraisal criteria. Six of them were quantitative studies and two were comparative: one found that those families who experienced greater (as opposed to lesser) volunteer involvement were significantly more satisfied with care; the other found that patients survived significantly longer if they had received home visits from a volunteer. Four cross-sectional studies focused on satisfaction ratings. No study considered possible disadvantages or adverse effects of volunteer involvement. Two qualitative studies were identified; both highlighted the uniqueness of the role volunteers may fulfil in care support, from the viewpoint of patients and their families.
Conclusions: Further research is needed to ensure the resource of volunteers in palliative care is used appropriately and effectively. Evaluation in well-designed comparative studies is recommended including economic analyses, as are further qualitative studies to explore the roles, benefits and possible adverse effects of volunteers. Evaluation is particularly needed outside of North America and in dedicated hospice facilities.

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What is already known about the topic?

- Volunteers are integral to palliative care, with many involved in the direct care of palliative care patients and their families.
- To meet demand palliative care services are increasing in number.
- Governments are seeking to increase the number of people who volunteer.

What this paper adds

- This systematic review found that the experience of palliative care patients and their families having a volunteer involved in their care and the impact a volunteer may have on their wellbeing are understudied.
- There is some limited evidence that palliative care interventions that involve volunteers have a positive impact on family satisfaction with care and may even lengthen patient survival.

1. Introduction

More people are dying from chronic diseases, and the demand for, and provision of palliative care is growing (Grant et al., 2011; Lynch et al., 2011; Morrison and Meler, 2011). This type of care may be needed over weeks or even months and there is growing recognition that provision should be for all, irrespective of age or diagnosis (Radbruch et al., 2013). The provision of specialist end-of-life care or palliative care varies across countries: what is more consistent is the extensive depth and breadth of volunteer involvement (Wright et al., 2008). Moreover volunteers were involved in the founding of the modern *hospice movement*, which, globally, provides a large proportion of palliative care (Centeno et al., 2013; Wright et al., 2008). In this setting volunteers contribute by: (1) directly supporting the provision of palliative care; (2) providing clinical support services such as clerical or laundry, and (3) fund-raising or being a trustee of a supporting voluntary organisation. A substantial proportion of volunteer contribution is in direct patient support, 60% in US (National Hospice and Palliative Care Organisation, 2012). In this role volunteers form part of the care team, supporting nursing care by undertaking task-orientated activities, such as serving patients' meals and drinks. They may also provide emotional or social support, such as spending time with the patient (Burbeck et al., 2014).

Palliative care service providers are likely to have difficulties sustaining current provision without volunteers; for example, in the UK it has been estimated that the 100,000 volunteers in hospices reduce service costs by 23% (Help the Hospices, 2012). There is the recognition of the need to increase the number of people who volunteer. In the UK, for instance, a Social Action Fund has been established to support programmes that encourage people to volunteer in their communities (UK Government, 2013). In Australia, the New South Wales Government has set-up a 10-year strategy to make it easier for individuals and organisations to meet regulatory requirements on volunteers. This involves streamlining processes and enhancing information resources to help organisations and prospective volunteers (NSW, 2012).

Recent systematic reviews have evaluated interventions where volunteers have been used as befrienders or as lay supporters such as those for people with depression (Lewin et al., 2010; Mead et al., 2010). It is important to evaluate the impact of all care services involving volunteers so that policy and practice is not based simply on lobbying, political expediency, or enthusiasm, but is informed by robust evidence on feasibility, acceptability and effectiveness. Moreover, while interventions are designed to provide benefit, it is important to consider possible risks, both long and short term as well as effects on patients' families. For example, in a systematic review of interventions to support carers of patients in palliative care it was found that one type of psychotherapeutic intervention potentially increased the risk of conflict in certain families (Candy et al., 2011). Thus, to maximise benefit and minimise risk, the involvement of volunteers in palliative care should be subject to the same independent scrutiny as other healthcare interventions.

There is no up-to-date critical and systematic review of the existing literature on the impact on patient and family wellbeing of services provided by volunteers with direct patient contact. Existing reviews take a broader or a different focus on the literature (Morris et al., 2013; Pesut et al., 2012; Wilson et al., 2005). For example, consideration of the evidence in regards to practice and organisation (Morris et al., 2013), and these reviews lack methodological inclusion criteria and quality assessment of included studies. Reporting methodological design features and assessing the conduct of included studies is important, without these the reader cannot differentiate between stronger and poorer evidence (Higgins and Green, 2011).

In this review we aimed to critically review research, evaluating outcomes relating to the wellbeing, and the experiences of palliative care patients and their families who receive care and/or support from volunteers.

2. Method

We reviewed quantitative and qualitative literature from 1990 to May 2013, following the methods set out by the Cochrane Handbook (Higgins and Green, 2011).

2.1. Eligibility criteria

2.1.1. Study designs

Randomised controlled trials are considered as the gold standard to evaluate the effects of an intervention. This study method more than any other reduces the risk of biased results. However, we did not anticipate identifying any studies of this design. This is in part because palliative care is under researched (Higginson et al., 2013). It is also because of ethical concerns in conducting research trials that involve withholding from a proportion of participants an additional element of care, which while not of