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[Intervention Review]

Training and supportive programs for palliative care volunteers in community settings

Dell Horey¹, Annette F Street², Margaret O'Connor³, Louise Peters³, Susan F Lee³

¹College of Science, Health and Engineering, La Trobe University, Bundoora, Australia. ²La Trobe University, Bundoora, Australia.

³Palliative Care Research Team, School of Nursing and Midwifery, Monash University, Frankston, Australia

Contact address: Dell Horey, College of Science, Health and Engineering, La Trobe University, Bundoora, VIC, 3086, Australia. d.horey@latrobe.edu.au.

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ABSTRACT

Background

Palliative care is specialised health care to support people living with a terminal illness and their families. The involvement of volunteers can extend the range of activities offered by palliative care services, particularly for those living in the community. Activities undertaken by palliative care volunteers vary considerably but can be practical, social or emotional in nature. The types of training and support provided to these volunteers are likely to affect the volunteers' effectiveness in their role and influence the quality of care provided to palliative care clients and their families. Training and support can also have considerable resource implications for palliative care organisations, which makes it important to know how to provide this training and support as effectively as possible.

Objectives

To assess the effects of training and support strategies for palliative care volunteers on palliative care clients and their families, volunteers and service quality.

Search methods

We searched the Cochrane Central Register of Controlled Trials (CENTRAL, *The Cochrane Library*, 28 April 2014); MEDLINE (1946 to 28 April 2014); EMBASE (1988 to 28 April 2014); PsycINFO (1806 to 28 April 2014); CINAHL (EbscoHOST) (1981 to 28 April 2014); ProQuest Dissertations and Theses (1861 to 28 April 2014). We also searched the Database of Abstracts of Reviews of Effects (DARE, *The Cochrane Library*); reference lists of relevant studies; and conducted an extensive search for evaluations published in government reports and other grey literature including the CareSearch database (www.caresearch.com.au (September 2004 to February 2012)) and websites of relevant organisations, for unpublished and ongoing studies.

Selection criteria

Randomised controlled trials (RCTs), quasi-randomised controlled trials, controlled before-and-after (CBA) studies and interrupted time series (ITS) studies of all formal training and support programs for palliative care volunteers. Programs or strategies in included studies were classified according to any stated or implied purpose: that is, whether they intended to build skills for the volunteer's role, to enhance their coping, or to maintain service standards.

Data collection and analysis

Two review authors screened 2614 citations identified through the electronic searches after duplicates were removed. The search of grey literature through websites yielded no additional titles. We identified 28 potentially relevant titles but found no studies eligible for inclusion.

Main results

We did not find any studies that assessed the effects of training and support strategies for palliative care volunteers that meet our inclusion criteria. The excluded studies suggest that trials in this area are possible.

Authors' conclusions

The use of palliative care volunteers is likely to continue, but there is an absence of evidence to show how best to train or support them whilst maintaining standards of care for palliative care patients and their families.

PLAIN LANGUAGE SUMMARY

Training and supportive programs for palliative care volunteers in community settings

The use of volunteers in community palliative care services can extend the range of activities offered to support people who are terminally ill. The types of training and support for volunteers are likely to affect their effectiveness and influence the quality of care provided to people requiring palliative care and their families. Training and support may also be costly for palliative care organisations.

The objective of this review was to assess the effects of training and support strategies for palliative care volunteers on people requiring palliative care and their families, volunteers and service quality. Despite extensive searching we found no studies that we could include. Research is needed on the impact of training and support for palliative care volunteers on patients, their families, volunteers and palliative care services.

BACKGROUND

Palliative care is specialised health care to support people living with a terminal illness and their families. The World Health Organisation defines palliative care as an approach that improves the quality of life of clients and their families facing life-threatening illness (Sepúlveda 2002; WHO 2009). Palliative care aims to prevent and relieve suffering, to help people to live as well as possible until they die, and to support the processes of dying and bereavement. The involvement of volunteers in formal programs can extend the range of activities offered by palliative care services (Freeman 1998; Chittazhathu 2005; Baines 2010; Wittenberg-Lyles 2010) and volunteers can comprise a considerable proportion of the palliative workforce headcount in some jurisdictions (DHS 2009). People in such volunteer roles are likely to need support, and this review sought to determine the most effective way to provide support to palliative care volunteers without compromising the focus on quality palliative care services for clients and families.

Despite wide use of the term 'volunteer', there is no internationally

recognised definition, but most existing definitions address four common issues: free will; availability and nature of remuneration; closeness of the recipient of volunteer services; and an affiliation with a formal agency (Hustinx 2010). This review defined a palliative care volunteer as someone who undertakes activities of benefit to the community of their own free will, with no financial payment (excluding reimbursements or nominal payments for expenses), in a designated volunteer position in a palliative care service or program in community settings.

A range of different service models for palliative care have developed (Higginson 2003; DoH 2008), which operate across a range of settings, including hospitals, hospices, homes, and residential aged care. The inclusion of bereavement within the scope of palliative care extends the reach to encompass resources for families after the death, in an attempt to minimise risks associated with complicated bereavement outcomes (O'Connor 2009). Multidisciplinary teams are common (Pastrana 2008) and many countries, both high- and low-income, include volunteers in their palliative care workforce (Igoe 1997; Francke 2000; Bollini 2004;

Gorospe 2006; DHS 2009; Luijkx 2009; Block 2010; Di Sorbo 2010; McKee 2010; Sévigny 2010; Wittenberg-Lyles 2010). The focus of this review is support for volunteers working with clients and their families in community settings, recognising that some clients may require inpatient palliative care services at some time. Community care is located in sites where people live or meet, as these contexts are where volunteers perform the broadest range of activities, are more likely to have more autonomy, and have less ready access to health professional support (Weeks 2008; Sévigny 2010).

The activities undertaken by palliative care volunteers in the community vary considerably across jurisdictions, and can be practical, social or emotional in nature. The involvement of palliative care volunteers can be directed to three main areas: the palliative patient; the patient's family or carers; and the palliative care organisation itself. This review is concerned with those palliative care volunteers working directly with clients and their families in their homes or community settings. These volunteers can be involved with clients in a number of ways. They can provide some form of practical basic patient care, such as helping with feeding or grooming (Herbst-Damm 2005). They can provide emotional support, by helping to discuss difficult issues (Luijkx 2009); social support, such as companionship (McKee 2010); or practical support, such as transporting clients and their families to and from appointments (Worthington 2008). Palliative care volunteers can provide similar types of support to families and carers before death (Luijkx 2009) and can also provide bereavement support (Weeks 2008).

There are practical reasons for including volunteers in palliative care teams, and although their widespread use means that it is not feasible to assess the effectiveness of their involvement in palliative care directly, there is some indication that they contribute positively to palliative care goals. A review of 44 studies, including at least 3 studies which had volunteers in the palliative care team, showed small but significant positive benefits from palliative care teams for clients, particularly for those cared for at home, in terms of reducing pain and relieving other symptoms (Higginson 2003). Assessing the impact of palliative care and subsequent volunteer involvement on other non-symptom related goals of palliative care poses significant challenges (Wong 2004; Albers 2010; Hales 2010), as there is little agreement on the most appropriate measures to use (Aspinal 2003; Higginson 2003; Jocham 2009; Pastrana 2010). However the availability of volunteers may influence two measures related to the palliative care goal of living as well as possible until death: length of survival (Herbst-Damm 2005) and place of death (Gomes 2013).

The types of support provided to palliative care volunteers are likely to affect their effectiveness in their role and influence the quality of care provided to palliative clients and their families.

Description of the intervention

Almost all organisations or agencies providing a palliative care volunteer program offer an orientation program to new recruits, which can be considered to be 'usual care'. This review is concerned with training and additional forms of support. The purpose of programs can be threefold: to develop skills in specific tasks to be undertaken; to enhance capacity to cope with the dying process and subsequent death; and to maintain service quality.

The focus of skill development is the specific needs of people who are dying and their families (Kumar 2007; Rolls 2008; Berry 2009). It can include communication training (Herbst-Damm 2005; Worthington 2008), or training on how to provide bereavement support (Weeks 2008).

Strategies to enhance coping seek to address the needs of volunteers, most commonly to help them to cope with death, and include screening for suitability for particular roles (McCallum 1989; Caidwell 1994), help with anxieties around death (Claxton-Oldfield 2007), and offering peer or mentor support (Seibold 1987).

Support programs with an organisational focus on service quality may involve team building or emphasise harm minimisation, for example by introducing codes of conduct (Fusco-Karmann 1998) or volunteer standards (DHS 2009), or by raising awareness of ethical issues (Freeman 1998; Gorospe 2006; Berry 2009).

How the intervention might work

Skill development programs for palliative care volunteers are similar to other training programs and are likely to work by increasing the knowledge, confidence and competence of palliative care volunteers to undertake their roles.

Strategies to support coping are likely to work by increasing volunteers' resilience to manage emotionally-demanding situations. Four reasons have been identified for high attrition among palliative care volunteers in some services: under-utilisation of volunteers by palliative care teams; late placement with patients; feelings of being undervalued by other palliative care team members; and restrictions in what can be done in the volunteer role (Claxton-Oldfield 2008). These are all unrelated to the capacity of volunteers to cope with dying people, or the skills needed for the role, and suggest that strategies that promote organisational support, such as involvement in palliative care team meetings, may be relevant.

Organisation support strategies may make better use of volunteers and may also improve the quality of palliative care. One study suggests four ways that volunteer visits might lead to longer survival (Herbst-Damm 2005). Volunteers may directly influence clients by increasing clients' feelings of control; by enhancing clients' emotional well-being; or by enhancing clients' appreciation for loved ones by helping them to find meaning (Mackay 2010). These three activities have the potential to strengthen immune function. The

fourth mechanism is indirect; through providing support to family caregivers, volunteers may relieve the burden of caring and so improve caregivers' well-being, which in turn may improve quality of care and support for clients.

Why it is important to do this review

While documenting the experiences of palliative care volunteers is important, the primary reason to invest in palliative care volunteers is to ensure the provision of quality palliative care for clients and families, while enhancing the volunteer experience. The provision of support to palliative care volunteers can have considerable resource implications for palliative care organisations, and as volunteers can extend the reach of a service considerably, it is important that any support provided to them is as effective as possible.

The role of volunteers is likely to grow. While palliative care was traditionally associated with cancer care, noticeable changes have occurred in the client population accessing such services (Addington-Hall 2002), in a manner consistent with the ageing demographic profile found in high-income countries, and the growing life spans in mid- and low-income countries. Demand has also been fuelled by equity expectations that quality dying is available to all, not just people with cancer; this is echoed internationally in population-based government policies (DoH 2008; Gomez-Batiste 2008; DoHA 2009).

Socio-cultural and demographic changes will affect the future of palliative care in two main ways. First, demand will be higher as the call for a 'good death' becomes more common, and second, the proportion of the population available for the health workforce overall will decrease, and is likely to be prioritised to areas concerned with managing chronicity and maintaining life, rather than quality of care at the end of life. Service models for palliative care throughout the world already use volunteers, and this trend is likely to increase. As palliative care extends its reach across social, cultural and economic boundaries, volunteers who match the socio-cultural attributes of the palliative care client group will need to be recruited (Jovanovic 2012).

One other Cochrane review addresses similar issues to this review. Candy 2011 is concerned with supporting informal caregivers of people with terminal illness, who are unpaid and provide "physical, practical and/or emotional care and support to a relative or friend." Our review differs in that participants do not have any previous relationship with the palliative care patient, and were associated with a formal volunteer program.

A second Cochrane review touches some common ground with this review as it is concerned with trained non-professionals carrying out healthcare functions (Lewin 2010). While our review examines support of a broader scope of palliative care volunteer activities than direct patient care alone, training in this aspect of care is a potential strategy to support palliative care volunteers.

This review aimed to assess the impact of training and supporting palliative care volunteers, on the clients of palliative care services,

palliative care organisations and on the volunteers themselves. It also sought to raise awareness of international differences in the use of volunteers and to identify the existence of any reliable tools to measure effectiveness or determine impact.

OBJECTIVES

To assess the effects of training and support strategies for palliative care volunteers on palliative care clients and their families, volunteers and service quality.

METHODS

Criteria for considering studies for this review

Types of studies

We intended to include randomised controlled trials (RCTs), quasi-RCTs (where the randomisation method used is subject to potential manipulation, for example allocation of study participants by day of week or sequence of entry to the trial), controlled before-and-after (CBA) studies and interrupted time series (ITS) studies. Future updates will consider only RCTs, cluster RCTs and quasi-RCTs. We anticipated few, if any, properly conducted studies, including RCTs, to have been done in this area; however, we also anticipated the possible inclusion of cluster RCTs, as interventions to support palliative care volunteers are commonly group based.

We intended to include CBAs if they had at least two intervention sites and two appropriate control sites, contemporaneous data collection, and comparable intervention and control groups in terms of key characteristics (specifically gender and age). We planned to include ITSs if they had a clear time point when the intervention occurred and at least three data points before and three after the intervention was introduced. While we planned to include quasi-RCTs, where the randomisation process could be potentially influenced, we did not specifically consider the inclusion of non-randomised trials in the review protocol (Horey 2011). However, we subsequently excluded trials if the study used wait-list controls, as allocation to the wait lists was not subject to any randomisation process.

Types of participants

We planned to include studies that involved participants as volunteers through a formal volunteer program in services offering palliative care in people's homes, residential aged care facilities or other settings in the community; we would also have included

studies that involved palliative care clients or their families receiving the services of such volunteers not in hospital.

We excluded studies involving informal carers and other volunteers not associated with a formal program. We also excluded studies involving people described as lay health workers or trained health professionals working without pay.

Types of interventions

We wanted to include all formal training and support programs for palliative care volunteers. Programs or strategies were to be classified according to any stated or implied purpose: that is, whether they intended to build skills for the volunteer's role (skill building), to enhance their coping (coping enhancement), or to maintain service standards (service quality). If necessary, we planned to give any programs that did not fit these classifications a post hoc categorisation.

We based these categorisations on the following criteria developed a priori. More than one category could be applied to a program. *Skill-building programs* include training to develop skills such as active listening, advance care planning, or bereavement support. *Coping-enhancement programs* include strategies such as screening for specific roles, mentorship, or linking with volunteer networks. *Service-quality programs* include strategies such as introducing codes of conduct or raising awareness of ethical issues.

Orientation programs that provided information about the palliative care service, but did not aim to build capacity in the volunteers in terms of skills or coping capacity, or that had a specific purpose of maintaining service quality, were to have been considered as 'usual care'. We intended to include any comparison group used in included studies.

Types of outcome measures

Primary outcomes

The primary outcomes of the review addressed its main focus, the impact on clients and families. These outcome categories are:

- evaluations of care (such as perceptions and ratings of volunteers by clients, families and other palliative care staff),
- psychological outcomes (such as anxiety, well-being, confidence, grief, compassion fatigue and resilience),
- pain-related outcomes,
- care outcomes (such as place of death, preferences met), and
- adverse outcomes (for example complaints by patients and families) as a primary outcome.

We included the adverse outcome category as a post hoc addition to the primary outcomes in response to the introduction of the Methodological Expectations of Cochrane Intervention Review (MECIR) standards by the Cochrane Collaboration in 2012.

While the assessment of quality of life in palliative care is important, it is problematic as there is a lack of consensus on what quality of life comprises and how it might be measured. None of the large number of tools used to measure quality of life in palliative care are validated. They also incorporate a broad spectrum of domains, few of which are common (Albers 2010). If the quality of life measures differ markedly, it is difficult to interpret pooled results across studies. We planned to include quality of life outcomes with caution; we would have categorised them as a psychological outcome if we had identified them as a primary outcome in an included study.

Secondary outcomes

The secondary outcomes of this review related to volunteers and palliative care services.

The outcome categories related to palliative care volunteers are:

- evaluations of support,
- skill acquisition,
- positive psychological outcomes (such as satisfaction with reciprocity, well-being, confidence, and resilience) and
- adverse psychological outcomes (such as anxiety, grief, and compassion fatigue).

Psychological outcomes, which initially described a single outcome category, were subsequently split into two separate outcomes in recognition that psychological outcomes can be beneficial or harmful.

Adverse outcomes was a post hoc inclusion as a primary outcome in response to the introduction of the MECIR standards by the Cochrane Collaboration in 2012.

The outcome categories related to health services are:

- cost,
- volunteer recruitment (such as rate and attrition), and
- adverse events (such as complaints).

'Summary of findings' tables for each of the target groups (palliative care clients and families, palliative care volunteers, and palliative care services) were to include those outcomes relevant to each group (as above).

Search methods for identification of studies

Problems were identified with the initial searches of electronic databases conducted in May 2012. We sought further expertise to redesign the searches, which were repeated in April 2014.

Electronic searches

We searched the following electronic databases:

- The Cochrane Consumers and Communications Review Group Specialised Register (28 April 2014);

- The Cochrane Specialised Register of Controlled Trials (CENTRAL, *The Cochrane Library*, 28 April 2014) ([Appendix 1](#));
- MEDLINE (OvidSP) (1946 to 28 April 2014) ([Appendix 2](#));
- EMBASE (OvidSP) (1988 to 28 April 2014) ([Appendix 3](#));
- CINAHL (EbscoHOST) (1981 to 28 April 2014) ([Appendix 4](#));
- PsycINFO (OvidSP) (1806 to 28 April 2014) ([Appendix 5](#));
- ProQuest Dissertations and Theses (1861 to 28 April 2014) ([Appendix 6](#)).

We also searched the Database of Abstracts of Reviews of Effects (DARE, *The Cochrane Library*) to identify potentially relevant reviews.

There were no language restrictions.

Searching other resources

As we did not identify any relevant studies we were unable to search the reference lists of included studies, contact authors, or conduct citation searches in the Science Citation Index database.

Grey literature

We undertook an extensive search for evaluations published in government reports and other grey literature. Three authors (MO'C, LP and SL) searched the CareSearch database (www.caresearch.com.au), from September 2004 to February 2012, and websites of relevant organisations including national and regional palliative care peak bodies, for unpublished and ongoing studies. All websites searched are listed in [Appendix 7](#).

International trials registers

We searched the following trial registry platforms to identify unpublished and ongoing studies using the terms 'palliative' and 'volunteer': Current Controlled Trials metaRegister of Controlled

Trials (www.controlled-trials.com) and the International Clinical Trials Registry Platform Search Portal (www.who.int/trialsearch). The sites were last searched on 24 November 2014.

Correspondence

We intended to contact the corresponding authors of any included studies to seek their help in identifying other possible studies.

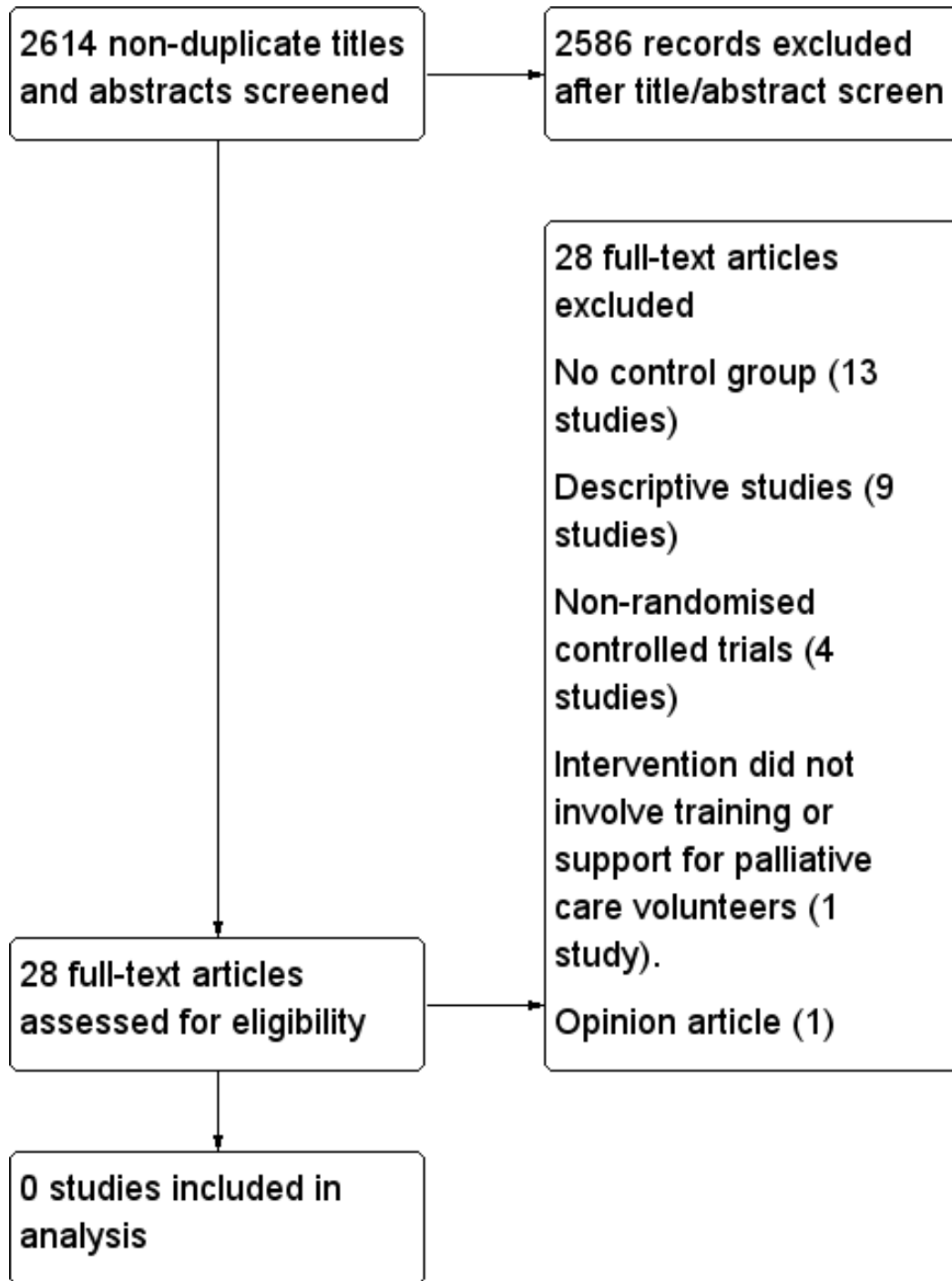
Data collection and analysis

Although no studies were identified for inclusion in this review, the following methods of data extraction, assessment of risk of bias, and data management will apply for subsequent updates of the review when future studies are identified. Future updates will include only RCTs and quasi-RCTs although the original protocol ([Horey 2011](#)) included provision for other study types. Details of our intended approach to the management of data from CBA and ITS studies can be found in [Appendix 8](#). All methods have been amended to meet the MECIR standards where necessary.

Selection of studies

Two authors independently screened all titles and abstracts identified from searches to determine which met the inclusion criteria. One review author (DH) screened all titles, which were also independently screened by at least one other review author. We retrieved in full text any papers identified by at least one author as potentially relevant. Two review authors independently screened full text articles for inclusion, with discrepancies resolved by discussion. If necessary we would have consulted a third author to reach consensus. In this review we also consulted a statistician (Dr Joanne McKenzie) to confirm issues related to study design. All potentially relevant papers excluded from the review are listed in the 'Characteristics of excluded studies' table with the reasons for exclusion provided. The screening and selection process is outlined in a PRISMA flow chart ([Liberati 2009](#)), see [Figure 1](#).

Figure 1. Flow diagram.



We found no included studies or ongoing studies. We intended to provide citation details and any available information about ongoing studies in a 'Characteristics of ongoing studies' table. Publications related to a single study would have been collated and reported so that each study (rather than each report) was the unit of interest in the review.

Data extraction and management

As we identified no studies for inclusion, this section details the approach that will be taken in future updates of this review when trials are identified.

Data from included trials will be extracted independently by two review authors using a data collection checklist based on the Cochrane Consumers and Communication Data Extraction template. We will develop and pilot a data extraction form using the Cochrane Consumers and Communication Review Group Data Extraction Template (available at: <http://cccr.org/cochrane.org/author-resources>) to extract details of included studies including characteristics of study participants (palliative care volunteers) and characteristics of the interventions (training or support programs). All data will be extracted and entered into RevMan (RevMan 2014) by one review author and checked for accuracy against the data extraction sheets by a second review author working independently. Data to be extracted includes:

- *Details of included studies:* aim of study; study design; method of recruitment; inclusion criteria and exclusion criteria; attrition overall and for each outcome; informed consent obtained (categorised as either yes, no or unclear); ethical approval (yes, no or unclear); funding (including source and amount); consumer involvement in study design (yes, no or unclear); declaration of interests by primary investigators (present, not present or unclear and reported details); types of outcome measures, how they were measured and their timing; outcome data and results.

- *Characteristics of palliative care volunteers:* definition of volunteers (including any reference to free will, financial payment and relationship to volunteer service recipients); criteria for palliative care selection; setting (home-based only, home and hospice, other); type(s) of care provided (direct patient care, direct patient support, family or carer support, bereavement support, unclear); descriptions of volunteer care; involvement of health professionals and retired health professionals as volunteers (yes/no/unclear), descriptions of such involvement.

- *Characteristics of training or support programs:* descriptive data about any intervention programs. Using the criteria reported in [Types of interventions](#) two authors will independently classify the aims of programs as either: skill-development coping-enhancement; service quality; other

purpose; or unclear. Programs will also be categorised as either single or multi-purpose. Classifications given by authors will be compared and any differences will be resolved by discussion until consensus is reached or through consultation with a third author where necessary. If any further categorisations are identified these will be described as post hoc and the defining criteria will be reported.

Assessment of risk of bias in included studies

We did not assess risk of bias as there were no included studies. When trials are identified in future updates the process to be undertaken is as follows:

We will assess and report on the methodological risk of bias of included studies using the 'Risk of bias' tool described in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011) and the guidelines of the Cochrane Consumers and Communication Review Group (Ryan 2013). These recommend explicit reporting of the following aspects of RCTs: random sequence generation; allocation sequence concealment; blinding (participants, personnel); blinding (outcome assessment); completeness of outcome data, selective outcome reporting; and other sources of bias (e.g. confounding and selective recruitment). We will consider blinding separately for different outcomes where appropriate (for example, if blinding has potential to differently affect a subjective outcome measure). We will judge each item as being at high, low or unclear risk of bias as set out in the criteria provided by Higgins 2011. In the 'Risk of bias' table we will provide justification for our judgement with support from direct quotes from study publications.

Studies will be deemed to be at the highest risk of bias if they are scored as at high or unclear risk of bias for either the sequence generation or allocation concealment domains, based on the growing empirical evidence of the important potential of these sources of bias (Higgins 2011).

Two authors will independently assess the risk of bias of all included studies and resolve any disagreements by discussion to reach consensus. If required we will contact study authors for additional information about an included study including clarification of study methods. We will incorporate the results of the 'Risk of bias' assessment into the review through standard tables, and systematic narrative description and commentary about each of the elements, leading to an overall assessment the risk of bias of included studies and a judgment about the internal validity of the review's results. Random sequence generation in quasi-RCTs will be assessed and reported as being at a high risk of bias. The selective recruitment of cluster participants will be an additional risk of bias domain assessed and reported for cluster RCTs.

Measures of treatment effect

As there are no included studies, we have reported no measures of treatment effect. The following approach will be taken in future updates of this review when trials are identified.

We will adopt the approach to the selection of measures of treatment effect as outlined by Brennan and colleagues (Brennan 2009) and consider all identified outcomes as outcome categories. We will use a systematic approach to identify the particular outcomes to be included in each category, based on the approach used by Horvat 2014.

Two authors will independently assign outcomes reported in each included study to the outcome categories determined for this review. Differences in outcome categorisation, should they occur, will be resolved by discussion with a third author.

Any primary outcome identified by publication authors assigned to the outcome categories will be included, unless multiple primary outcomes are identified. If this occurs we will rank the intervention effect estimates of these outcomes, as reported in the publication, and select the outcome with the median effect estimate. Where possible we will verify that the specified primary outcomes reported by study publications are consistent with those nominated in trial protocols and/or trial registry entries. When no primary outcome is specified, we will use the outcome specified in the sample size calculation. If there are no sample size calculations, we will rank the intervention effect estimates, as reported in the publication, and select the median effect estimate. When there is an even number of outcomes, we will include the outcome whose effect estimate is ranked $n/2$, where n is the number of outcomes.

We will also report any common outcomes within the outcome categories, but these results will be additional findings. In results tables we will report whether we have used the primary outcome or the outcome with the median effect estimate.

Dichotomous outcomes

For dichotomous outcomes, we will analyse data based on the number of events and the number of people assessed in the intervention and comparison groups. We will use these to calculate the risk ratio (RR) and 95% confidence interval (CI). The effect estimates will be standardised so that ratios greater than one, and differences between the intervention and comparator groups greater than zero, represent benefit for the intervention group.

Continuous outcomes

For continuous measures, we will analyse data based on the mean (pre- and post-intervention), standard deviation ($SD_{pre,pooled}$), which is the pooled standard deviation of the two groups pre-intervention) and number of people assessed for both the intervention and comparison groups to calculate standardised mean difference (SMD) and 95% CI using the inverse variance method in Review Manager 5.3. If the mean difference is reported without individual group data, we will use this to report the study results.

Unit of analysis issues

As there were no included studies no unit of analysis issues arose. In future updates clustering will be addressed in the following way: We will check studies in which clusters of individuals are randomised (cluster RCTs and controlled clinical trials (CCTs)) to intervention groups for unit of analysis errors. Where inference is intended at the level of the individual we will re-analyse data using the appropriate unit of analysis by taking account of intra-cluster correlation (ICC). Estimates of the ICC will be obtained by contacting authors of included studies, or imputed using external estimates if possible. Where it is not possible to obtain sufficient information for re-analysis we will report effect estimates annotated with 'unit of analysis error'.

Dealing with missing data

When trials are identified in future updates of this review we do not plan to undertake any imputation for missing outcome data but to impute missing summary data where possible and report any assumptions in the results tables. In any meta-analysis the effect of the selected ICC on the pooled effect estimate will be assessed through sensitivity analyses.

We will attempt to contact study authors to obtain missing data (participant, outcome, or summary data). For participant data, we will, where possible, conduct analysis on an intention-to-treat basis; otherwise data will be analysed as reported. We will report on the levels of loss to follow-up and assess this as a source of potential bias.

Assessment of heterogeneity

When trials are identified in future updates of this review heterogeneity will be assessed in the following way.

Where studies are considered similar enough (based on consideration of the aims of the training or support programs) to allow pooling of data using meta-analysis, we will assess the degree of heterogeneity by visual inspection of forest plots and by examining the Chi^2 test for heterogeneity. Heterogeneity will be quantified using the I^2 statistic. An I^2 value of 50% or more will be considered to represent substantial levels of heterogeneity, but this value will be interpreted in light of the size and direction of effects and the strength of the evidence for heterogeneity, based on the P value from the Chi^2 test (Higgins 2011). Where heterogeneity is present in pooled effect estimates we will explore possible reasons for variability by conducting subgroup analysis.

Where we detect substantial heterogeneity in terms of methodology, statistics or the aims of the training or support programs across included studies, we will not report pooled results from meta-analysis. Instead we will use a narrative approach to data synthesis and attempt to explore possible clinical or methodological reasons for this variation by grouping studies that are similar in terms of program aims to explore differences in intervention effects. As we

expect few studies, we will be cautious in our interpretation of the Chi² test, as few trials mean little power to detect heterogeneity.

Assessment of reporting biases

In future updates of this review, we will assess biases as follows. In addition to an extensive search of the published and grey literature, we will search the International Clinical Trials Registry Platform Search Portal and Current Controlled Trials *meta*Register of Controlled Trials to identify other trials that may not be published or are currently underway, and we intend to contact the relevant investigators for further information. We will assess reporting bias qualitatively based on the characteristics of the included studies (e.g. if only small studies that indicate positive findings are identified for inclusion), and if information that we obtain from contacting experts and authors of studies suggests that there are relevant unpublished studies.

If we identify sufficient studies (at least 10) for inclusion in the review we will construct a funnel plot to investigate small study effects, which may indicate the presence of publication bias. We will formally test for funnel plot asymmetry, with the choice of test made based on advice in Higgins 2011, and bearing in mind that there may be several reasons for funnel plot asymmetry when interpreting the results.

We anticipate heterogeneity in effect estimates because of variability in the interventions. We plan to use the approach identified by Brennan 2009, and developed by Rücker and colleagues, which proposes a statistical test when substantial between-study heterogeneity exists when data points are proportions (Rücker 2008).

Data synthesis

As no studies were identified for inclusion in the review this section details the approach to data synthesis in future updates.

If we are unable to pool the data statistically using meta-analysis we will conduct a narrative synthesis of results. We will report summary statistics for the major outcomes and results for each comparison organised by the aims of the training programs (skill-development; coping-enhancement; service quality; other purpose; and unclear). We will use graphs to display data graphically where feasible. Results will be organised by the intervention categories, which will be determined by the aims of the training and support programs. Within these data categories we will explore the main comparison of the review, that is the training or support program versus usual care (orientation program). If a meta-analysis is performed, we will use a random-effects model.

Subgroup analysis and investigation of heterogeneity

When studies are identified in future updates we plan to carry out subgroup analyses based on differences in the focus of interventions (skill-development; coping-enhancement; service quality). If

feasible we will compare single purpose programs with multipurpose programs (for example, we will compare programs identified as skill-development only with other programs that combine skill-development with coping-enhancement and/or service quality).

Sensitivity analysis

In future updates we plan to undertake sensitivity analyses based on the 'Risk of bias' assessment, with studies at the greatest risk of bias, as described in the 'Risk of bias' tables, removed from the analysis. We will also investigate if the pooled intervention effect is robust to our assumptions of ICCs if cluster RCTs are included.

'Summary of findings' table

As there were no included studies we were unable to prepare 'Summary of findings' tables. In future updates we will present the results of meta-analyses in 'Summary of findings' tables based on the methods described in Chapter 11 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Schünemann 2011), for each of the target populations (palliative care clients and families, palliative care volunteers, and palliative care services). The primary outcomes for this review are concerned with the impact of volunteer training and support on palliative care clients and their families, however decisions about such programs are also likely to take account of their impact on the palliative care volunteers, and the palliative care services.

We will present the results of meta-analysis for the major comparisons of the review, for each of the outcomes, including potential harms, as outlined in the [Types of outcome measures](#) section. We will provide a source and rationale for each assumed risk cited in the table(s), and will use the GRADE criteria to rank the quality of the evidence using the GRADEprofiler (GRADEpro) software (Schünemann 2011). If meta-analysis is not possible, we will present results in a narrative 'Summary of findings' table format, such as that used by Chan 2011.

Consumer participation

Two important groups of potential users of this review are people who are palliative care volunteers themselves, and people who may use their services. We involved these two groups by using an existing network of palliative care volunteers in Victoria, Australia, and members of the Cochrane Consumer Network. The draft protocol and draft review were circulated to these groups for consumer peer review. The review team sent the draft protocol and review to two palliative care volunteers working in community settings. In addition the editorial team of the Cochrane Consumers and Communication Review Group involved members of the Cochrane Consumer Network to provide comments on the protocol and the review.

RESULTS

Description of studies

Results of the search

The searches of electronic databases generated 2614 citations after we removed duplicates. The search of grey literature through websites added no additional potentially relevant studies (see [Table 1](#)). After screening titles and abstracts we identified 28 potentially relevant studies and retrieved full texts to assess each paper (see [Figure 1](#)).

Included studies

No studies were eligible for inclusion.

Excluded studies

We excluded 27 studies and 1 opinion publication. Excluded studies included trials that used wait-lists for the control group (4 studies). It is unclear whether such studies can be considered non-randomised controlled studies (see [Higgins 2011](#)) when allocation to a wait-list is not arbitrary. None of these studies assessed the primary outcomes for this review. Baseline data for 2 studies did not allow comparison as they were incomplete ([Retallack 1985](#); [Werner 1990](#)) or not reported separately ([Barrack 1985](#)). In 1 study members of the control group did not subsequently volunteer ([Hayslip 1985](#)). We excluded other studies because they did not have a control group (13 studies), were descriptive studies (9 studies), or because the intervention did not involve training or support for palliative care volunteers (1 study). There were 6 doctoral and 2 masters theses among the excluded studies, all completed in North America, with the majority (7 of 8) published between 1981 and 1990 (see [Characteristics of excluded studies](#)). There are no studies awaiting assessment and we are not aware of any ongoing studies.

Risk of bias in included studies

No studies were included in this review.

Effects of interventions

None of the studies retrieved in our searches met the review's inclusion criteria.

DISCUSSION

Summary of main results

No studies met the inclusion criteria for this review.

Despite the wide use of volunteers in palliative care in the community and the associated investment to train and support them, there are no well designed studies that provide good evidence to guide palliative care volunteer training and support to ensure good outcomes for palliative care patients and their families, and for palliative care volunteers, or value for palliative care services.

The lack of studies in this area is an important finding of this review, given the increasing role of volunteers in community palliative care across the world. Volunteers with palliative care services are likely to work with many dying people and families across a range of circumstances and the management and support of a volunteer workforce is likely to grow as the profile of populations and health workforces change and demands for good quality care until the end of life grow. The lack of studies to determine effective training and support for palliative care volunteers should be considered in comparison with the review of interventions to support informal caregivers of palliative patients ([Candy 2011](#)), which identified 11 RCTs, 9 of which were published in 2005 or later.

Overall completeness and applicability of evidence

We looked for studies that included participants in formal volunteer programs where support was available to them but found no studies that met the inclusion criteria for this review.

Potential biases in the review process

This review used broad approaches to searching and the expertise of an experienced professional to ensure that all relevant studies could be identified. This is a field of study with considerable variation in practice and the terminologies used. It is possible that studies were missed because of language issues, although we ensured that language of publication was not an exclusion criterion. Our decision to include a broad range of study types is indicative of the trade-offs necessary for a review to establish any level of evidence in a neglected area of study.

Agreements and disagreements with other studies or reviews

Four reviews of the literature on palliative care volunteers have been published since 2005 ([Wilson 2005](#); [Morris 2013](#); [Pesut 2014](#); [Candy 2015](#)). All had limited search periods that overlap (from 1988 to May 2013) and included a mix of study designs, with five observational studies common to the three more recent reviews ([Herbst-Damm 2005](#); [Weeks 2008](#); [Luijckx 2009](#); [Block](#)

2010; Claxton-Oldfield 2010). Three reviews were limited to publications in English (Wilson 2005; Morris 2013; Pesut 2014) and only one appraised the included studies (Candy 2015). Wilson 2005 and Pesut 2014 had broad, largely descriptive aims, whereas Morris 2013 undertook a narrative review to examine organisational issues related to palliative care volunteers. Candy 2015 sought to establish the impact of volunteers involved in the direct care of palliative patients and their families. Candy 2015 followed the methods set out in the *Cochrane Handbook* (Higgins 2011), somewhat modified, for example both comparative and non-comparative studies were included.

Volunteer training and other organisational needs or requirements was one of themes identified in the Wilson 2005 review, which also pointed to wide variation in the roles undertaken by palliative care volunteers. The review questioned whether such volunteers are used effectively, although this observation was not specifically linked to training needs. Pesut 2014 also described a broad role for palliative care volunteers and linked volunteer involvement to patient-centred care. However the review authors also suggested that palliative care volunteers may not get enough education on cultural competency or communication. Morris 2013 identified the issues of stress and coping among palliative care volunteers, nominating stressors such as lack of training and emotional support. Candy 2015 refers to the diverse activities undertaken by palliative care volunteers, and in the eight studies included in the review, these range from what appear to be social visits in the home to the provision of basic care. Two studies refer to training, which included the provision of patient care and family support (Jack 2011) and training for listening and providing conversation (Herbst-Damm 2005). The lack of clear role definition for hospice volunteers was also a feature noted in this review.

In the only systematic review, Candy 2015, which examined the impact of volunteers directly caring for palliative patients or their families, looked-for outcomes related to patient and family well-being, satisfaction with care and use of services and treatments. However only two outcomes were reported: patient survival and satisfaction with care. Although not explicitly stated, patient survival appears to have been considered to be a measure of patient well-being, with patient survival data obtained from an audit. Patient survival was found to increase among those who had volunteer visits. The involvement of volunteers was also associated with increased patient and family satisfaction with care in several studies, all at high risk of bias.

The authors of all reviews agreed on the need for further research in this area.

AUTHORS' CONCLUSIONS

Implications for practice

The use of palliative care volunteers is likely to continue but there is an absence of evidence to show how best to train or support them whilst maintaining standards of care for palliative care patients and their families.

Implications for research

There is need for research into the training and support needs of palliative care volunteers and the resultant impact on patients, their families, volunteers and palliative care services, including foundation work with studies to determine consensus on the goals of involving palliative care volunteers, understanding of the tasks performed by volunteers in the community and identifying ways to integrate volunteers into palliative care services. Training and support interventions should be evaluated in rigorously designed studies across different population groups that are sufficiently powered to detect meaningful differences. Excluded studies, in particular 4 trials that used wait-list controls, in which allocation to the wait-list was not arbitrary or resulted in groups that were not comparable, all conducted at least 25 years ago, suggest that rigorous research in this area is possible. Cluster randomised trials are likely to provide the best way to approach such evaluations to ensure that potential confounders are appropriately addressed. Such studies should set out to assess the impact on patients and their families, such as their possible influence on achieving preferred place of death and liaising with health professionals, as well as on the volunteers themselves and palliative care services. There is also a need to give attention to monitoring any potential adverse effects.

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Wittenberg-Lyles E, Schneider G, Parker OD. Results from the national hospice volunteer training survey. *Journal of Palliative Medicine* 2010;**13**(3):261–5.
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- References to other published versions of this review**
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of Systematic Reviews 2011, Issue 12. [DOI: 10.1002/
14651858.CD009500]

* *Indicates the major publication for the study*

CHARACTERISTICS OF STUDIES

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Barrack 1985	Non randomised controlled trial with wait-list used as control group
Burnett 1983	Descriptive study only
Chou 2008	Descriptive study only
Claxton-Oldfield 2007a	No control group
Claxton-Oldfield 2007b	No control group
Downey 2009	Intervention does not involve training or support for palliative care volunteers
Dush 1988	Descriptive study only
Hall 1996	Descriptive study only
Hayslip 1985	Non randomised controlled trial with wait-list used for control group
Janson 1997	No control group
Kim 1998	No control group
Lafer 1989	No control group
Lamb 1985	Descriptive study only
Lorbach 2003	Descriptive study only
MacLeod 2012	No control group
McIntosh 1988	No control group
Nakaishi 1981	No control group
Paradis 1987	Descriptive study only
Rabow 2002	No control group
Retallack 1985	Non randomised controlled trial with wait-list control group
Robbins 1992	Descriptive study only

(Continued)

Scherwitz 2006	No control group
Seibold 1987	No control group
Shuff 1997	Descriptive study only
Tamlyn 1985	No control group
Werner 1990	Non randomised controlled trial with wait-list used for control group
Wilkinson 1986	No control group
Wilson 2000	Opinion article

DATA AND ANALYSES

This review has no analyses.

ADDITIONAL TABLES

Table 1. Results of search of grey literature

Source searched	Date	Potential inclusions	Result
Meta Register of Controlled trials, (www.controlled-trials.com/mrct/search.html)	21 Jan 2012	1 result from search engine. REST - Reducing End of life Symptoms with Touch. [NIH ClinicalTrials.gov Register (International) - subset of randomised trial records]. Purpose of study to determine whether massage therapy is effective in reducing pain and distress and improving quality of life among cancer patients at life's end. Study used volunteers to provide intervention. Not a study of volunteer support interventions	No relevant studies
Meta Register of Controlled trials, (www.controlled-trials.com/mrct/search.html)	21 Jan 2012	8 results from search engine related to interventions regarding patient care. 'Voluntary' referred to voluntary consent	No relevant studies
International Clinical Trials Registry Platform Search Portal (www.who.int/trialsearch)	1 Jan 2012	299 records for 286 trials checked. 1 possible study excluded as it referred to spousal carers rather than designated volunteers	No relevant studies
International Clinical Trials Registry Platform Search Portal (www.who.int/trialsearch)	21 Jan 2012	0 results from search engine.	No relevant studies
CareSearch (www.caresearch.com.au/)	31 Jan 2012	0 results from search engine.	No relevant studies
The National Gold Standards Framework (UK) (www.gold-standard-framework.nhs.uk ; www.gold-standardsframework.org.au)	21 Jan 2012	3 results from search engine: 1 briefing, 1 newsletter, 1 evaluation of Gold Standards Framework	No relevant studies
NHS UK (www.nhs.uk)	21 Jan 2012	1050 results from search engine including: 1 press release case study of a volunteer; 1 press release re volunteers helping staff 11 Aug 2011 (not referring to research). Others related to stories about	No relevant studies

Table 1. Results of search of grey literature (Continued)

		volunteering including participating in clinical trials	
International Association for Hospice and Palliative Care (www.hospicecare.com)	21 Jan 2012	No research reports.	No relevant studies
International Observatory on End of Life Care (www.lancs.ac.uk/shm/research/ioelc/)	21 Jan 2012	49 results from search engine but all excluded including 4 descriptive studies with focus on volunteer roles rather than interventions to support and 1 related to advance care planning	No relevant studies
Help the Hospices (www.helpthehospices.org.uk/)	21 Jan 2012	496 results from search engine but none were reports of courses, training or support for volunteers	No relevant studies
Asia Pacific Hospice Palliative Care Network (APHN) (aphn.wordpress.com)	21 Jan 2012	List of press releases only.	No relevant studies
World Palliative Care Alliance (www.thewpca.org)	21 Jan 2012	260 results from search engine but all referred to press releases, developing country strategies, toolkit, or training manual	No relevant studies
International Volunteer Programs Association (www.volunteerinternational.org)	21 Jan 2012	15 results from search engine but none related to palliative care	No relevant studies
Oxford International Centre for Palliative Care (www.sobell-hospiceoxford.org)	21 Jan 2012	5 results from search engine but related to jobs and testimonials	No relevant studies
Palliative Care Australia (www.palliativecare.org.au)	21 Jan 2012	Only links to annual reports, bulletins, strategic plans.	No relevant studies
Japan Hospice Palliative Care Foundation (www.hospat.org/english/future.html)	21 Jan 2012	No research reports.	No relevant studies
African Palliative Care Association (www.apca.org.ug)	21 Jan 2012	7 results from search engine related to publications but not related to volunteers. Link to toolkit for establishing services	No relevant studies
Canadian Hospice Palliative Care Association (www.chpca.net)	21 Jan 2012	No research listed.	No relevant studies

Table 1. Results of search of grey literature (Continued)

Indian Association of Palliative Care (www.palliativecare.in)	21 Jan 2012	No research directly listed but training described on site and links to journals via Indian Journal of Palliative Care, Cochrane and the International Association for Hospice and Palliative Care (IAHPC)	No relevant studies
National Hospice and Palliative Care Organization (www.nhpco.org)	21 Jan 2012	Members only access to performance measures. Volunteers not mentioned	No relevant studies
Family Health International (www.fhi.org/en/index.htm)	21 Jan 2012	41 results from search engine but these relate to news or reports on service development and delivery, testimonials, or refer to voluntary counselling and testing in relation to HIV	No relevant studies
Volunteering Australia (www.volunteeringaustralia.org)	21 Jan 2012	4 results from search engine relate to press releases and reference to two reports: Lee, Shirley. Reflections of Volunteers in Palliative Care; and ECU 2005 Volunteers contributing to a palliative approach in aged care: A model for helping out. Searches on Google Scholar could not locate these	Two potential reports (which look to be descriptive accounts) could not be found
WHO (www.who.int)	25 May 2012	Searches conducted in January 2012 (21 and 31 January) and May 2012 (24 and 25 May). Total of 2290 results from search engine. Nothing relevant identified although 7 reports and 1 peer-reviewed publication were retrieved and assessed for inclusion These were descriptive studies. No studies identified that reported support or training for palliative care volunteers	No relevant studies found
NICE (http://www.nice.org.uk)	25 May 2012	Total 40 results (3 from “palliative + volunteer” and 37 from “palliative + voluntary”) One possible study excluded - Workforce training standard had no references to relevant studies. See http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/WorkforceTraining.jsp	No relevant studies found
Red Cross (www.redcross.org.au)	25 May 2012	No studies found.	No relevant studies found

Table 1. Results of search of grey literature (Continued)

International Volunteering Research (www.ivr.org.uk)	21 Jan 2012	Two descriptive studies identified.	No relevant studies found
CRUSE Bereavement Care (www.crusebereavementcare.org.uk) Organisation for the recruitment, training and support of bereavement volunteers	21 Jan 2012	Reference to 2 possible studies but these excluded. 1 was a feasibility study of volunteer program rather than an intervention to support volunteers, and the other, specifically related to AIDS, describes task shifting which involves training lower qualified staff to retain knowledge in resource poor areas	No relevant studies found

APPENDICES

Appendix 1. CENTRAL

IDSearch

#1palliative:ti,ab,kw

#2((terminal near/3 (care or patient*)):ti,ab,kw

#3((terminal* or endstage or end-stage or advanced-stage or late-stage or last-stage or final-stage) near/3 (ill* or disease* or cancer*)):ti,ab,kw

#4(dying or end-of-life):ti,ab,kw

#5(hospice* or bereavement or bereaved):ti,ab,kw

#6{or #1-#5}

#7(voluntary near/3 (work* or care* or service* or support* or involvement or health* or hospice* or palliative or help* or counsel* or staff or personnel or provider* or group* or organi*ation* or association* or agenc* or communit* or network* or sector* or program*)):ti,ab,kw

#8volunteer*:ti,ab,kw

#9[mh "hospital volunteers"]

#10hospital-auxiliar*:ti,ab,kw

#11{or #7-#10}

#12#6 and #11 in Trials

Appendix 2. MEDLINE (Ovid SP) search strategy

1. palliative care/

2. palliative.tw.

3. terminal care/

4. (terminal adj2 (care or patient*)).tw.

5. terminally ill/

6. ((terminal* or endstage or end stage or advanced stage or late stage or last stage or final stage) adj3 (ill* or disease* or cancer*)).tw.

7. (dying or end of life).tw.

8. hospice care/

9. hospices/

10. bereavement/
11. (hospice* or bereavement or bereaved).tw.
12. or/1-11
13. volunteers/
14. voluntary health agencies/
15. exp hospital volunteers/
16. volunteer*.tw.
17. (voluntary adj3 (work* or care* or service* or support* or involvement or health* or hospice* or palliative or help* or counsel* or staff or personnel or provider* or group* or organi#ation* or association* or agenc* or communit* or network* or sector* or program*)).tw.
18. hospital auxiliar*.tw.
19. or/13-18
20. 12 and 19
21. randomized controlled trial.pt.
22. controlled clinical trial.pt.
23. clinical trial.pt.
24. evaluation studies.pt.
25. comparative study.pt.
26. random*.tw.
27. placebo*.tw.
28. trial.tw.
29. research design/
30. follow up studies/
31. prospective studies/
32. cross over studies/
33. (experiment* or intervention*).tw.
34. (pre test or pretest or post test or posttest).tw.
35. (preintervention or postintervention).tw.
36. time series.tw.
37. (cross over or crossover or factorial* or latin square).tw.
38. (assign* or allocat*).tw.
39. (control* or compar* or prospectiv*).tw.
40. (impact* or effect? or chang* or evaluat*).tw.
41. or/21-40
42. 20 and 41

Appendix 3. EMBASE search strategy

1. exp palliative therapy/
2. palliative nursing/
3. palliative.ti,ab,kw.
4. terminal care/
5. (terminal* adj3 (care or patient*)).ti,ab,kw.
6. exp terminally ill patient/
7. terminal disease/
8. ((terminal* or endstage or end stage or advanced stage or late stage or last stage or final stage) adj3 (ill* or disease* or cancer*)).ti,ab,kw.
9. (dying or end of life).ti,ab,kw.
10. hospice care/
11. hospice nursing/
12. hospice/
13. bereavement/
14. bereavement counseling/
15. (hospice* or bereavement or bereaved).ti,ab,kw.

16. or/1-15
17. voluntary worker/
18. voluntary program/
19. volunteer/
20. volunteer*.ti,ab,kw.
21. (voluntary adj3 (work* or care* or service* or support* or involvement or health* or hospice* or palliative or help* or counsel* or staff or personnel or provider* or group* or organi#ation* or association* or agenc* or communit* or network* or sector* or program*)).ti,ab,kw.
22. hospital auxiliar*.ti,ab,kw.
23. or/17-22
24. 16 and 23
25. randomized controlled trial/
26. controlled clinical trial/
27. single blind procedure/ or double blind procedure/
28. crossover procedure/
29. random*.tw.
30. trial.tw.
31. placebo*.tw.
32. ((singl* or doubl*) adj (blind* or mask*)).tw.
33. (experiment* or intervention*).tw.
34. (pre test or pretest or post test or posttest).tw.
35. (preintervention or postintervention).tw.
36. (cross over or crossover or factorial* or latin square).tw.
37. (assign* or allocat* or volunteer*).tw.
38. (control* or compar* or prospectiv*).tw.
39. (impact* or effect? or chang* or evaluat*).tw.
40. time series.tw.
41. or/25-40
42. 24 and 41

Appendix 4. CINAHL search strategy

#	Query	Limiters/Expanders	Results
S12	s11	Limiters - Exclude MEDLINE records Search modes - Boolean/Phrase	295
S11	s6 and s10	Search modes - Boolean/Phrase	777
S10	s7 or s8 or s9	Search modes - Boolean/Phrase	24,454
S9	"hospital auxiliar*"	Search modes - Boolean/Phrase	6
S8	volunteer*	Search modes - Boolean/Phrase	22,202
S7	voluntary N3 (work* or care* or service* or support* or involvement or health* or hospice* or palliative or help* or counsel* or staff or personnel or provider* or	Search modes - Boolean/Phrase	2,649

(Continued)

	group* or organi?ation* or association* or agenc* or communit* or network* or sector* or program*)		
S6	s1 or s2 or s3 or s4 or s5	Search modes - Boolean/Phrase	52,644
S5	hospice* or bereavement or bereaved	Search modes - Boolean/Phrase	17,436
S4	dying or “end of life”	Search modes - Boolean/Phrase	15,145
S3	(terminal* or endstage or “end stage” or “advanced stage” or “late stage” or “last stage” or “final stage”) N3 (ill* or disease* or cancer*)	Search modes - Boolean/Phrase	13,652
S2	terminal N3 (care or patient*)	Search modes - Boolean/Phrase	11,097
S1	palliative	Search modes - Boolean/Phrase	24,067

Appendix 5. PsycINFO search strategy

1. palliative care/
2. palliative.ti,ab,id.
3. terminally ill patients/
4. (terminal* adj3 (care or patient*)).ti,ab,id.
5. terminal cancer/
6. ((terminal* or endstage or end stage or advanced stage or late stage or last stage or final stage) adj3 (ill* or disease* or cancer*)).ti,ab,id.
7. (dying or end of life).ti,ab,hw,id.
8. hospice/
9. (hospice* or bereavement or bereaved).ti,ab,hw,id.
10. or/1-9
11. volunteers/
12. volunteer*.ti,ab,id.
13. (voluntary adj3 (work* or care* or service* or support* or involvement or health* or hospice* or palliative or help* or counsel* or staff or personnel or provider* or group* or organi#ation* or association* or agenc* or communit* or network* or sector* or program*)).ti,ab,id.
14. hospital auxiliar*.ti,ab,id.
15. or/11-14
16. 10 and 15

Appendix 6. ProQuest Dissertations & Theses Global

(Command Line Search)

all(palliative or (terminal near/3 (care or patient*)) or ((terminal* or endstage or “end stage” or “advanced stage” or “late stage” or “last stage” or “final stage”) near/3 (ill* or disease* or cancer*)) or dying or “end of life” or hospice* or bereavement or bereaved) and all(volunteer* or (voluntary near/3 (work* or care* or service* or support* or involvement or health* or hospice* or palliative or help* or counsel* or staff or personnel or provider* or group* or organi*ation* or association* or agenc* or communit* or network* or sector* or program*)) or “hospital auxiliar*”)

Appendix 7. Grey literature: Websites searched

The National Gold Standards Framework (UK) (<http://www.goldstandardsframework.nhs.uk>);
International Association for Hospice and Palliative Care (www.hospicecare.com);
NHS UK (www.nhs.uk);
International Observatory on End of Life Care (www.lancs.ac.uk/shm/research/ioelc/);
Help the Hospices UK (www.helpthehospices.org.uk);
National Institute for Health and Clinical Excellence UK (www.nice.org.uk);
Asia Pacific Hospice Palliative Care Network (www.apfn.org);
Worldwide Palliative Care Alliance (<http://www.thewpca.org>);
Family Health International (www.fhi.org/en/index.htm);
Red Cross (www.redcross.int);
WHO (www.who.int);
International Volunteer Programs Association (www.volunteerinternational.org);
Oxford International Centre for Palliative Care (www.sobellhospiceoxford.org);
Volunteering Australia (www.volunteeringaustralia.org).

National and regional palliative care peak bodies

African Palliative Care Association (www.apca.org.ug);
Palliative Care Australia (www.palliativecare.org.au);
Canadian Hospice Palliative Care Association (www.chpca.net);
Indian Association of Palliative Care (www.palliativecare.in);
Japan Hospice Palliative Care Foundation (www.hospat.org/english/future.html);
National Hospice and Palliative Care Organization (www.nhpco.org).

Appendix 8. Method proposed for management of CBA and ITS studies

Assessment of risk of bias

Controlled before-and-after (CBA) studies

We planned to assess CBA studies against the same criteria as RCTs, that is the domains from the 'Risk of bias' tool: random sequence generation; allocation concealment; blinding (participants, personnel); blinding (outcome assessment); completeness of outcome data, selective outcome reporting; and other sources of bias (confounding and selective recruitment of participants). We planned to consider blinding separately for different outcomes where appropriate (for example, blinding may have the potential to differently affect subjective versus objective outcome measures) and to judge each item as being at high, low or unclear risk of bias as set out in the criteria provided by Higgins 2011. In the 'Risk of bias' table we would have cited from the study publication and reported a justification for our judgement. Consistent with current standards we intended to report CBA studies as being at high risk of bias in terms of random sequence generation and allocation sequence concealment. We intended to exclude any CBA studies in which the groups were not reasonably comparable at baseline.

Interrupted times series (ITS)

We planned to assess and report on the following items for ITS studies: intervention independence of other changes; pre-specification of the shape of the intervention effect; likelihood of intervention affecting data collection; blinding (participants, personnel); blinding (outcome assessment); completeness of outcome data, selective outcome reporting; and other sources of bias (confounding and selective recruitment of participants).

Measures of treatment effect

All outcomes were to be reported by study design.

CBA studies

For all included outcomes, we would have extracted the reported effect estimate with its P value and confidence interval (CI), and the method of statistical analysis used to calculate it. If an inappropriate statistical method had been used, we would not present the P value or CI unless we were able to re-analyse the data, where we would annotate the P value as 're-analysed' in the results tables.

We will follow the approach described by [Brennan 2009](#) to calculate the effect estimates for:

- dichotomous outcomes (RR, adjusted RR) for baseline or risk differences using the number of events and the number of people assessed in the intervention and comparison groups.
- continuous outcomes (standardised mean difference, relative percentage change post intervention, mean differences post intervention, and difference in mean change).

P values for these effect estimates would have been calculated. Effect estimates were to be standardised so that scales and other outcome measures were concordant. Ratios greater than one, and differences between the intervention and comparator groups greater than zero would indicate benefit for the intervention group, so effect estimates would be multiplied by minus one where necessary.

ITS

For ITS studies we intended to report the following estimates, and their P values, from regression analyses which adjust for autocorrelation: (i) change in level of the outcome at the first point after the introduction of the intervention (immediate effect of the intervention), (ii) the post-intervention slope minus the pre-intervention slope (long term effect of the intervention).

Unit of analysis issues

Clustering

In CBA studies clusters of individuals are allocated to intervention groups and we would have checked to confirm whether inference was intended at the level of the individual. If so, we would have needed to re-analyse data appropriately to account for correlation of observations within clusters by making assumptions about the intra-cluster correlation (ICC). Estimates of ICC would be obtained from contacting authors, or imputed, using external estimates from similar studies or using general recommendations from empirical research ([Campbell 2000](#)). If this was not possible we would have reported the effect estimate and annotated the phrase 'unit of analysis error'.

ITS studies

ITS studies have been shown to be frequently incorrectly analysed ([Ramsay 2003](#)) with statistical methods which do not account for the autocorrelation of data points. We planned to re-analyse results from such studies where we were able to obtain the data from the authors, or from data presented in graphs or tables in the publication. Time series regression analysis accounting for first order autocorrelation would have been used to analyse the data and estimate a change in level of the outcome at the first point after the introduction of the intervention, and the post-intervention slope minus the pre-intervention slope ([Ramsay 2003](#); [Austvoll-Dahlgren 2008](#)). Confidence intervals would be calculated for these effect estimates.

Data synthesis

We would have reported summary statistics for each comparison from any included CBAs including: baseline and follow-up summary statistics; effect estimates and their statistical significance; and information on effect modifiers and study design. We planned to summarise effect estimates for dichotomous outcomes within each comparison and study design. This would have included the median effect estimate, inter-quartile range, and range. We would have used graphs to display data graphically.

If possible, we planned to use meta-analytical methods to pool relative risks measuring the effectiveness of different strategies to support palliative care volunteers focused on skill development and/or coping enhancement and/or service quality using orientation programs as the comparator. Random-effects meta-analysis would have been used to pool intervention effects because of anticipated clinical and methodological diversity. We planned to report an approximate 95% range of underlying effect estimates, based on the between-study variance estimate, to provide some information on the spread of effect estimates (Higgins 2009).

We planned to present results from ITS studies in tables for each comparison, with summary statistics for each of the included studies, change in level of the outcome at the first point after the introduction of the intervention, post-intervention slope minus the pre-intervention slope, and information on effect modifiers. This would have also been presented graphically using, for example, scatter plots of change in level versus change in slope with combinations of statistical significance denoted by different symbols.

WHAT'S NEW

Last assessed as up-to-date: 28 April 2014.

Date	Event	Description
13 January 2015	Amended	Methods were updated to meet the requirements of the MECIR standards and to exclude controlled before-and-after studies and interrupted time series studies from future updates

CONTRIBUTIONS OF AUTHORS

The review was conceived by all review authors, who also all contributed to its preliminary design. The protocol (Horey 2011) was planned and written by DH, with contributions from AS. LP designed the original search strategy. All authors were involved in aspects of the search. MO'C, SL and LP were responsible for searching the grey literature. DH and AS screened all titles and abstracts and DH collated all retrieved papers. DH with AS and SL independently applied inclusion criteria. All authors were to be involved in the resolution of any discrepancies in data extraction and 'Risk of bias' assessment if they had occurred. DH was responsible for writing the review. All authors contributed to interpretation and development of the review's conclusions.

DECLARATIONS OF INTEREST

None known

SOURCES OF SUPPORT

Internal sources

- Faculty of Health Sciences, La Trobe University, Australia.
Salaries
- Palliative Care Research Team, Monash University, Australia.
Salaries

External sources

- No sources of support supplied

DIFFERENCES BETWEEN PROTOCOL AND REVIEW

The review was updated from the protocol ([Horey 2011](#)) to meet the MECIR standards introduced in 2012. In addition, methodological aspects of the review were clarified, specifically aspects of the categorisation of the review outcomes and how they were to be managed. The methodology was amended to reflect the approach to be used in future updates.

INDEX TERMS

Medical Subject Headings (MeSH)

*Family; *Palliative Care; Volunteers [*education]

MeSH check words

Humans