

# Supporting caregivers of palliative care patients — Respite and other caregiver interventions and evidence of their efficacy

A literature review



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# Executive summary

The initial purpose of this paper was to identify and document the scientific evidence in relation to the use of respite in supporting caregivers of palliative care patients.

Gathering and reviewing this information was undertaken to examine the underlying assumptions that providing respite to caregivers of palliative care patients improves patient and/or caregiver outcomes in three key domains:

- more palliative care patients being able to die in their place of choice compared to those patients who do not receive respite
- superior symptom management (medical, social, spiritual, psychological) compared to those patients who do not receive respite
- lower levels of carer stress/burden compared to those patients who do not receive respite.

An additional aim was to gather and review any literature that assessed whether respite provision improves the efficiency of the health system more broadly; for example, by preventing unwarranted emergency department admissions.

A desktop review of the available literature (search terms encompassed 'palliative care' and 'respite') revealed only limited support for the efficacy of respite as an intervention on its own. Evidence for its efficacy was stronger for studies employing quasi-experimental/descriptive methods than for more rigorous study designs.

The key learning from this literature review is that caring for carers is not just about respite provision, and from a policy perspective, solely investing in respite would be unlikely to achieve the desired caregiver and patient impact. In fact, the provision of respite may not be the most important element in making a difference to caregiver outcomes. A more appropriate strategy would be to focus on understanding the most effective package of services that benefit caregivers in their role of supporting palliative care patients, and making sure that these are implemented systematically for each and every carer who is a client of a specialist palliative care service.

Given the limited evidence for the efficacy of respite, the scope of the literature review was widened to include a broader review of caregiver interventions (not just respite alone) intended to improve caregiver and patient outcomes for people receiving palliative care. Extensive use was made of the resources section detailed on the website of the International Palliative Care Family Carer Research Collaboration (IPCFRC) to inform the widened scope of this literature review.

A broad suite of caregiver needs have been identified in the literature (Kristjanson et al. 2003, cited in Aoun et al. 2005) with respect to:

- patient comfort
- information needs
- practical care needs
- emotional support.

Effective communication between health professionals and families has also been identified as an important caregiver need (Aoun et al. 2005; Ventura et al. 2014).

Accordingly, the material contained in this literature review has mainly been organised according to the categories of family caregiver need identified above.

A variety of recommendations has been made in the palliative care literature about the best ways to meet this broader set of carer needs which are detailed in the body of this literature review.

There is also a great deal already known about what caregivers of palliative care patients need to support them in their role and to avoid the negative outcomes associated with caring for a person with terminal illness. There is also a lot that is unknown, and there is a clear role for continuing research to discover new interventions and/or improve the ones that already exist.

Following the lead of McCorkle and Pasacreta (2000; 2001, cited in Palliative Care Australia 2004) a potentially promising approach may be to test caregiver interventions over time with homogenous groups of patients at specific points on the illness trajectory (trajectory onset, crisis, acute, unstable, downward and dying). Some interventions could be most effective at certain points in the illness trajectory, while others could be protective across several stages. While the literature does document the nature and type of interventions that are effective in many circumstances, there does not appear to have been a concerted effort to test the effectiveness of caregiver interventions according to the conceptual model proposed by McCorkle and Pasacreta, nor are suggested caregiver interventions documented at the level of specificity envisaged by their model.

It is also recommended that a tailored environmental scan/survey be distributed to specialist palliative care providers for completion in order to facilitate further policy development in this area. This is because there is hardly any current documented evidence available to the Department of Health & Human Services (henceforth, the department) that provides detail on which providers offer which types of respite (in-home, in-hospital, centre based) or other forms of carer support, how they target clients in most need or what outcomes are achieved for clients of respite services and other carer support services and how these outcomes are measured. The survey could be structured in such a way as to incorporate the best practice approaches identified in the literature review to determine which services already adopt best practice approaches and what the gaps exist, with a view to remodelling respite and other carer support services in line with best practice.

In a study of service preferences among family caregivers of the terminally ill in Canada (Brazil et al. 2005), the five most requested support services were housekeeping, respite, in-home nursing, personal support workers and self-help groups.

As a first step to configuring an appropriate service system, it would also seem logical to determine service preferences among caregivers of the terminally ill in Victoria. The department has already captured much of this information in the questions posed through the Victorian Palliative Care Satisfaction Survey (VPCSS), which also substantially addressed the relevant categories of carers' needs as documented in the palliative care literature. The contract for the conduct of the VPCSS expired in June 2014. At the time of writing, the department is in the process of deciding how the needs of carers of people with a terminal illness will be measured. While the specifics are not yet known, in line with developments in the field of 'patient satisfaction', in the future, the department will be moving to an assessment of patient experience rather than solely focusing on satisfaction, because such an approach fails to capture significant information about the delivery process and quality of the service received, which hinders quality improvement.

For example, client and carer satisfaction has been continually high across the palliative care sector, yet it is reasonable to expect that a client may still have experienced service delivery problems at some point in their care. Identifying these experiences offers areas for further improvement.

Satisfaction surveys focus on one aspect of the client's experience, and may not adequately represent the aspects most relevant to the client along their entire journey. In contrast, experience measures ask clients and/or carers to comment on the occurrence of certain events and processes, rather than how satisfied they were with the overall episode of care.

Questions that are focused on satisfaction can fail to provide specific information that can be applied to quality improvement processes. In contrast, experience questions seek factual responses regarding what may or may not have happened during an episode of care, providing information that can be directly applied.

Notwithstanding the above, there is a clear opportunity to investigate the nature of caregiver needs and preferences in greater depth. This is because the VPCSS only provided summary-level information on some of the domains of caregiver need. Therefore, the proposed environmental scan will allow the department to get a more comprehensive understanding of the nature of support provided to carers of palliative care patients, with a view to reshaping the service system so that it better meets the needs of carers.

What needs to be done is to make sure that what is known, at an 'acceptable' evidence level, is systematically implemented for all carers of palliative care patients. Accordingly, the literature review examines some of the findings from the field of implementation science/knowledge translation to guide action in this critical area.

This literature review, and the proposed environmental scan of specialist palliative care providers in Victoria, represent an important step in understanding what carers need and when and will drive practice improvement and facilitate further ongoing research to fill the gaps in our knowledge of how to support caregivers of the terminally ill.

The ultimate aim would be to construct a palliative care service system that provides the optimum mix and quantum of interventions and/or services to carers, and in so doing, maintain their resilience and ability to continue in their caring role for as long as reasonably feasible.

## 2. Introduction

The initial aim of this paper was to explore the scientific evidence supporting the use of respite to support caregivers of palliative care patients.

The underlying assumptions (hypotheses) guiding this paper were that respite can:

- improve outcomes for patients
- improve outcomes for carers
- improve outcomes for the health system more broadly (for example, preventing unwarranted emergency department admissions or provide savings to the acute sector by preventing inappropriate admissions to specialist inpatient palliative care services).

After reviewing the available literature on respite, which involved a desktop review of relevant journal articles up to 2014, it became apparent that there were limited rigorous intervention studies supporting its efficacy, although there was more support for the hypotheses outlined above from quasi-experimental and/or descriptive studies.

Accordingly, it was decided to broaden the scope of the literature review, and in the latter part of the paper there is a review of broader caregiver interventions (not just respite) intended to improve the outcomes of caregivers of palliative care patients as well as patients themselves.

## 3. Role of carers

Family carers are an important source of support for older adults living in the community (Grinfeld et al. 2004, Dumont et al. 2006, cited in *Guidelines for a Palliative Approach for Aged Care in the Community Setting — Best practice guidelines for the Australian context* 2011) and a vital component of the health care team that provides a palliative approach to care.

Without the support of family carers, many people with chronic and life-limiting illness would be unable to continue to live at home (Covinsky et al. 2001, Grov et al. 2006, *ibid*).

Until recently, family carers were viewed as ‘helpers’ (Given et al. 2004). However, the intensity of the impact of caring on carers’ health (Redinbaugh et al. 2003, Grunfeld et al. 2004, Dumont et al. 2006, *ibid*) and the widespread nature of this impact (Gonzalez-Salvador et al. 1999, Meuser and Marwit 2001, *ibid*.) have now been recognised, leading to a heightened awareness of the risks associated with caring (Brazil et al. 2005a, *ibid*). In Australia, most family carers are women who do not work full time; they also tend to be in poor health (Lee and Gramotnev 2007, *ibid*).

## 4. Carer experience

Carers of people near the end of life experience considerable physical, psychological, social and financial challenges (Ingleton et al. 2003).

Aoun et al. (2005) has detailed the negative impacts of caregiving for people with a life-limiting illness. Sources of stress include uncertainty about treatment, lack of knowledge about patient care, role changes within the family, lack of transportation for treatment, strained financial resources, physical restrictions, lack of social support and fears of being alone. Disruptions and emotional strains associated with caregiving are common experiences for families of people with cancer. Feelings of tiredness, difficulty getting enough sleep and feelings of resentment and isolation were the most commonly reported disruptions and emotional strains and among the most difficult coping challenges. Caregivers suffered from lack of control over everyday life, lack of self-confidence, changes in paid employment, reduction in leisure time, deterioration in their own health, exacerbation of a previous health problem, postponement of their own health care and feelings of distress.

Harding et al. (2012), in a systematic literature review of carer interventions and their effectiveness, reiterate the many negative aspects of informally caring for someone with a cancer or advanced incurable disease, including sleeplessness, general deterioration in health, exhaustion and anxiety/depression. They also highlight the distinctive challenges of trying to improve outcomes for caregivers in cancer and palliative care (compared to, for example, informal care of the elderly, in mental health or disabled populations) — in that only a relatively brief window of opportunity is available in which to learn new methods of coping, to put these methods into practice and to achieve an improvement in outcome.

## 5. Risk factors for adverse carer outcomes

The *Guidelines for a Palliative Approach for Aged Care in a Community Setting* (the 'Guidelines'), published in 2011 by the Australian Government Department of Health and Ageing and approved by the National Health and Medical Research Council, identify a number of risk factors that can predispose carers to adverse outcomes and which can be used by service providers to prioritise care.

The risk factors are:

- providing live-in care (Visser et al. 2004), especially when the care recipient has dementia (Banerjee et al. 2003)
- having difficulty with managing the person's symptoms, medications and self-care needs (Redinbaugh et al. 2003)
- looking after older people with higher levels of dependency (Ferrario et al. 2004), including a higher risk of falls (Kuzuya et al. 2006)
- experiencing a disrupted lifestyle; for example, needing to be absent from work or to abandon work activities (Ferrario et al. 2004)
- having a low level of education (Lee et al. 2001)
- having two or more health conditions (Lee et al. 2001)
- looking after someone whose physical or psychological symptoms are causing them distress (Redinbaugh et al. 2003; Tilden et al. 2004)
- having difficulty communicating with the care recipient (Fried et al. 2003)
- experiencing losses in social life, family relationships and leisure activities (Kesselring et al. 2001).

Similarly, Girgis et al. (2006) identifies caregiver groups at risk of poorer psychological outcomes and higher levels of caregiver burden, as detailed below:

- caregiver wives, who have higher levels of depression and poorer health than caregiver husbands
- those with smaller social networks
- those with lower perceived caregiver satisfaction and higher perceived levels of stressful behavioural and self-care problems as exhibited by the patient
- those with higher levels of anxiety
- those with higher levels of anger
- those who care for patients with higher levels of need
- those caring for longer periods
- caregivers who are younger (< 65 years)
- caregivers with limited social networks and more restrictions in their daily activities due to caregiving.

## 6. Definition of respite

There are various definitions of respite in the literature. There is no consensus definition and sometimes it is contested.

Keefe and Manning (2005) define respite as 'a break, time out or relief for the caregiver' (p.4). They stress that there is 'no exactness to its measurement and it is unrealistic to expect total relief from stress and burden but rather only aspects of it' (p.7).

Ingleton et al. (2003) describe respite as both a service and an outcome. As a service, it includes inpatient care, day care, or home-based care. It is designed to produce a positive effect on the carer to enable them to continue in their role (outcome).

Ingleton et al. (2003) state that definitional boundaries between 'respite' and 'symptom control' as reasons for referral to specialist palliative care services are often blurred. It is possible that referral for respite care to specialist palliative care services functions more to support members of the health care team who may be struggling with a complex patient care situation, than assisting informal carers by the provision of respite. This contention is further supported by a discussion paper written by the Southern Metropolitan Region Palliative Care Consortium in 2006, whereby clinicians in specialist inpatient palliative care services stated that: 'there was confusion in the community about the definition of respite in palliative care, and that often request for respite were really an indication that there were symptom management issues, or there was a functional deterioration of the patient that indicated disease progression, so that request for respite admissions were often not simply for carer respite' (p.11).

In a survey of specialist palliative care providers of inpatient respite in the UK, Payne et al. (2004) found that while the majority of respondents agreed that respite is predominantly for the benefit of carers, a large proportion also disagreed, believing that respite should predominantly benefit the patient or mutually benefit the patient and carer.

In Payne et al.'s 2004 study, respite was differentiated by some respondents into:

- a 'pure', 'straightforward', 'true' or 'simple' palliative care that excluded the need for symptom control or implied the need for social rather than medical care
- others perceived of respite care as 'specialist', 'high intensity' support or provision of 'specialist nursing needs'
- a few indicated an 'emergency category' of respite care.

## 7. Types of respite

Generally speaking, respite to palliative care patients and their carers is provided according to the following service delivery models:

- Inpatient respite. This involves admission of the patient to a specialist palliative care ward in an acute hospital setting. In addition to respite, such an admission may involve symptom assessment and control, investigatory and medical interventions requiring monitoring and terminal care.
- In-home respite (daytime). As the term suggests, provision of daytime respite allows carers to attend to myriad household tasks and also provides an opportunity for carers to socialise. If

provided by volunteers, the patient needs to be independent in activities of daily living and medically stable for this to be viable.

- In-home respite (overnight). This mode of respite is intended to provide carers with opportunities to sleep. It can be provided on an emergency or planned basis. The complexity of care required will determine the discipline of the respite carer, but they are generally nurses or personal care assistants.
- Day hospice. Day hospice care provides activities and therapies for patients with life-limiting illness. The patient attends a day centre and participates in activities offered, as desired. The patient needs to be reasonably independent — although there is the ability to provide limited support with activities of daily living.

## 8. Some nuances of respite

Satterley (2007), cited in Wolkowski et al. (2010), rightly stresses that if the primary purpose of respite care is to benefit the carer, one might assume that patients would not necessarily require medical or nursing interventions during respite (Satterley 2007) above what they would normally receive at home. However, a number of UK studies have shown that this is not the case, with the most commonly reported reason for respite care in hospices being the patient's symptom management.

Intriguingly, McNally et al. (1999) caution against an overly idealistic view of the benefits of respite, claiming that it has the potential to increase future strain by creating more problems to be coped with after the intervention period. In particular, if after respite a care recipient's functional disability or need for care has increased, then this is likely to negate any improvements in carer wellbeing experienced during intervention and prevent any enduring benefits.

Ingleton et al. (2003) make the point that the uptake of respite is low even when it is available. Reasons posited for this finding include the fact that carers make judgments about the relative costs and benefits of accepting help, reject services inconsistent with their needs, or which they consider to be of poor quality. Carers want help that is consistent yet flexible and responsive, addresses the needs of the person they care for, respects their individuality and promotes a good quality of life.

## 9. Evidence in relation to the efficacy of respite

### 9.1 Background

In the national and international literature, the provision of respite care is frequently mentioned as a critical factor in enabling carers to care for longer and have an improved quality of life. However, Wolkowski et al. (2010) question how respite care could have reached such an elevated position in the carer needs hierarchy, given that 'there is a lack of research to support its efficacy and little is known about respite services for patients with a life-limiting illness'. The authors go on to say that because anecdotal evidence for the benefits of respite is so strong 'it is almost as if...it does not require research'.

## 9.2 Summary of findings

Based on an analysis of the reviewed literature, it is apparent that there is limited rigorous evidence to support the contention that respite care improves patient and/or caregiver outcomes. However, what evidence there is in support of the efficacy of respite care is contained in less rigorous studies; whereas randomised controlled trial (RCT) evidence is not as supportive of its efficacy.

## 9.3 Detailed findings

With respect to **findings from rigorous research**, the *Guidelines for a Palliative Approach for Aged Care in the Community Setting — Best practice guidelines for the Australian context* (2011) (which were based on detailed research of relevant literature, written by palliative care experts and approved by the National Health and Medical Research Council) made the following practice-based recommendations with respect to the provision of respite care.

### **Guideline 4.1 — Respite care — Support for family carers**

#### *Effects of respite care for carers of older adults with moderate or severe dementia*

Respite care should be available to support family carers of people with moderate or severe dementia.

This recommendation was based on evidence obtained from the literature review, which found that there is level I and II evidence of the effect of respite care on a variety of carer outcomes, including burden, depression, wellbeing, stress, sleep, coping, worry, anger and adrenalin levels. On balance, respite care had benefits for carers of older people with moderate or severe dementia (but this had only a limited clinical impact).

#### *Effects of respite care for carers of generally frail or unwell older adults*

Respite care should be routinely available to support family carers of generally frail or unwell older adults. (This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.)

This recommendation was based on evidence obtained from the literature review, which found that there is level I evidence with a low risk of bias of the effect of respite care on depression in carers of generally frail or unwell older adults. The results showed consistently that respite care had a moderate positive and clinically meaningful effect on depression.

#### *Effects of respite care for family carers of older adults with advanced cancer, severe chronic heart failure or other specific advanced disease or condition*

There is currently insufficient evidence to indicate whether respite care should be made available to support family carers of older adults with advanced cancer, severe chronic heart failure or other specific advanced disease or condition.

Taken from *Guidelines for a Palliative Approach for Aged Care in the Community Setting — Best practice guidelines for the Australian context* (2011) p. 141.

However, it is important to note that the literature search period which generated the above recommendations spanned from 1997 to 2007. It is an open question as to whether the results of research conducted since 2007 would lead to a revision of the above evidence-based practice recommendations.

With respect to **findings from quasi-experimental or descriptive studies**, the findings in relation to the efficacy of respite seem more promising, although due to the weaker study design, caution is advised when trying to decipher implications for policy or program design.

The most relevant study identified from an Australian perspective was conducted by Barret et al. (2009). In this study, the authors evaluated an at-home palliative care respite service delivered by enrolled nurses. They chose this model of intervention based on previous studies that identified that carer concern over the skill of respite care providers is a barrier to uptake and satisfaction with respite services. The intervention was implemented in Geraldton, Western Australia. The project was conducted over a 25-week period. Respite was limited to seven daytime hours per week overall. A total of 41 patients were eligible over the study period with an average caseload of 29 patients per week.

The key findings of interest from the study were that:

- After adjusting for matching variables (age, sex and condition), patients receiving respite care were 80 per cent less likely to be hospitalised than historical controls.
- Of the patients who received respite, all but one died at home. All historical controls died in hospital. In the case of the patient who died in hospital, this setting was the preferred location of death.
- If hospital bed days in the intervention group had been as high (without respite care) as that predicted by the historical control, the effect of the program would have been \$AU34,375 in hospital-bed-saved days over the 25 weeks. Following removal of costs to implement the program, a total saving of \$AU13,900 would remain. If the implementation were modified to follow a systematic implementation protocol, rather than as a 'pilot' intervention, the cost of running a program in Geraldton for one year would be around \$23,816. This would involve utilising administrative staff for data entry and an RN for the application of the assessment tool. Based on the predicted reduction in hospital bed days, the value of these bed days over one year would be \$71,500. Thus it is estimated that the total cost saving to the health service would be \$47,684 per year in the region.

In a somewhat similar vein, a Canadian study (Kristjanson et al. 2004 cited in Keefe and Manning 2005) evaluated a night respite service offered to caregivers of 53 palliative care patients in eleven months. The findings suggested that at least some patients would have been transferred to an inpatient setting for end-of-life care, but were able to die at home with this support.

In terms of other published research, McNally et al. (1999) conducted a systematic review of the effects of respite care on informal carers' wellbeing. Of the studies reviewed, the most popular outcome in the evaluation of respite was psychological wellbeing, operationalized through standardised measures of carers' depression, anxiety, mood or morale (17 studies). However, the results of the reviewed studies suggests that respite intervention does not have a consistently beneficial effect, with only 10 reporting improvements in psychological wellbeing, and six reporting no effect. Of the 13 studies that measured carer stress/burden, only eight studies report improvements attributable to respite, four reporting no effect, with the remaining study finding that respite only benefited carers of stable patients.

An interesting observation to come out of the above systematic review was that improvements in psychological wellbeing were only maintained for up to one week after the end of respite before returning to baseline levels.

Zarit et al. 1998 (cited in Ingleton et al. 2003) make the point that optimum service impact depends on a number of factors: if used in insufficient amounts, or too late in the lifespan of the caregiving experience, caregiver burden and stress are not reduced as much as when services are used before burden and stress are substantially felt, on a regular basis and in sufficient amounts.

McNally et al. (1999) indicate that the efficacy of respite varied according to the type of respite offered. The models of respite included 'in-patient' residential respite care, out-of-home 'day care', out-of-home 'overnight' care, and 'in-home' respite (which usually involved scheduled visits from a nurse/care assistant).

Of the six studies that looked at the effects of in-home care alone, only two reported improvements. In contrast, of the six studies examining the exclusive effect of in-patient respite on psychological wellbeing/carer stress, five reported improvements. This may reflect the more complete respite from the pressures of caring offered by in-patient care, which is likely to provide carers with more options in how they spend their time (for example, a holiday), to spare the carer the particularly stressful 'sun-up' and 'sun-down' tasks (for example, lifting in and out of bed), and also to improve the quantity and quality of sleep, all of which in-home respite may fail to do.

In a similar vein, Mason et al. (2007) also conducted a systematic review of the efficacy of various respite models — adult day care, respite packages, in-home respite and multidimensional packages.

For adult day care, randomised evidence suggests that day care neither benefited nor harmed care receivers, although results from quasi-experimental studies were more positive. For example, Zarit's (1998) study (cited in Mason et al. 2007) found that caregivers using 'substantial' amounts (at least twice a week for at least three months) of day care benefited significantly more than those using no day care, in terms of caregiver depression and caregiver burden ('overload'), and that day care appeared to delay entry to institutional care.

For respite packages (that is, interventions involving more than one type of respite) evidence from randomised studies reported that only marginal benefits (that is, they were slightly more relieved and more satisfied with support) accrued to caregivers relative to those in the control group.

Again evidence from quasi-experimental studies were more promising, reporting reductions in caregiver stress, improvements in caregiver morale and reduction in subjective burden.

In a US study by Grant et al. 2003 (cited in Mason et al. 2007) which examined the effects of in-home respite for 55 dyads, no effect was found on caregiver vulnerability (defined as a severe mismatch between caregiving demand and help received in the preceding six months), but appeared to moderate stress-related chemical levels in the subgroup of 'vulnerable' caregivers.

Clark et al. 2000 (cited in Mason et al. 2007) evaluated a pilot initiative known as the 'Macmillan Carers Schemes' provided at seven sites in the UK. The pilot scheme offered respite as part of a multidimensional package.

A team of healthcare assistants provided practical support, personal care (for patients) and emotional support to patients with cancer and their caregivers. In addition to in-home respite and companionship, support included help with washing, dressing, cooking and other activities of daily living.

The evaluation of 624 service users found that respite for caregivers was the principal reason for referral (42 per cent of all referrals). When surveyed about their satisfaction with the respite services, 86 per cent of the 121 caregivers who responded felt able to go out and leave the assistant in charge.

In their systematic review, McNally et al. (1999) found that 'social factors' may influence the effectiveness of respite intervention — in that respite needs to focus on facilitating social contacts and relationships in order for more long-lasting effects to be achieved.

This may in part explain why any gains in wellbeing are often not maintained for long after the end of a respite intervention. In order for improvements to become less transitory it may be necessary that resources such as social relationships are reinvigorated during respite. McNally et al. describe a study by Hinchcliffe et al. that involved not only respite, but also a comprehensive program tailored to individual carers' needs. One of the issues addressed was the development of independent social activities outside

the home. Carers receiving this intervention exhibited a significant improvement in mental health (as assessed by the General Health Questionnaire) which was maintained at a 16-week follow-up.

## 10. Targeting of respite

The *Guidelines for a Palliative Approach for Aged Care in a Community Setting* (the 'Guidelines') published in 2011 by the Australian Government Department of Health and Ageing provides some guidance to service providers in prioritising access to respite services. The Guidelines identified family carers in most need of respite as those who:

- provide high levels of support with personal care, and are unable to access blocks of free time (Braithwaite 1998, Kosloski et al. 2001)
- are in dysfunctional caring relationships (which often involve a history of conflict between the carer and the care recipient) (Braithwaite 1998)
- experience increasing distress, for whatever reason (Kosloski et al. 2001).

## 11. A note about conflicting findings from respite intervention studies

Eagar et al. (2007), in their report on effective caring, decry the poor definition of carer support interventions. The result is that the systematic reviews effectively synthesise different interventions. Respite care is used as a prime example of this shortcoming — it may be planned or unplanned, provided in different locations (home, centre or residential) and provided at various levels of service intensity (one-off, daily, weekly, monthly and so on). But there are few reviews that control for different service models or that have attempted to measure dose effects (for example, is weekly respite care more effective than, say, respite once a month?). As a result, Eagar et al. (2007) conclude that it is not surprising that various reviews and studies report different findings.

The lack of robust evidence for the benefits of respite care was a theme echoed by participants in a workshop on 'effective caring' hosted by the University of Wollongong in 2007 and attended by key service delivery and academic experts. Eagar et al. (2007) state that there is a need to unpack and define the meaning of respite and its expected effects in the context of a systematic model of caring, because these effects may well differ among carers depending on factors such as the characteristics and diagnosis of the care recipient and the care situation.

They argue it would be feasible to conduct a systematic evaluation of respite, varying factors such as type, dose and timing. It is also important to understand the factors that lead to a need for respite, and whether these can be predicted. Conversely, why do some people resist respite care? Workshop participants agreed that there was considerable demand for respite: most carers say they need it. Given this fact, the question for research is 'what kind of respite works best (in what circumstances)?'.

Unfortunately, based on the literature sourced as part of this current literature review, there does not appear to have been much headway made in the ensuing years in answering the above questions about respite.

Despite the conflicting findings identified in the research literature, the value of carer respite is formally recognised through the provision of a range of respite options provided by specialist palliative care services and through the existence of the Commonwealth National Respite for Carer's Program (NRCP)

which aims 'to contribute to the support and maintenance of caring relationships between carers and care recipients by facilitating access to information, Respite Care and other support appropriate to the carer's individual needs and circumstances, and those of the care recipient' (National Respite for Carers Programme, *Respite Service Providers' Programme Manual*, July 2014, p. 17). Carers of people with a terminal illness requiring palliative care are part of the target population of the NRCP.

## 12. Expressed needs of carers of palliative care patients and carer support interventions

Palliative care patients and their caregivers have a wide range of needs, not just for respite services. Given the limited information in the published literature about the efficacy of respite, it was decided to take a broader look at the other interventions that aim to support caregivers of palliative care patients and to provide a commentary on their efficacy. The aim of this exercise is to see if the literature can provide some hints as to where to best invest limited public funds to get the most impact for palliative care patients and their carers.

Carers of palliative care patients have expressed a range of needs (not just those related to respite) which have been documented in the literature.

Kristjanson et al. (2003), cited in Aoun et al. (2005), report that in palliative care, four types of family care needs are consistently identified:

- patient comfort/pain management
- information needs
- practical care needs
- emotional support.

With regards to **patient comfort**, management of pain is one of the essential goals of palliative care. The family can interpret the patient's pain as a sign of progressive illness and impending death and report feelings of desperation and helplessness if they cannot comfort the patient effectively (Kristjanson et al. 2003)

The literature documents a myriad of caregiver concerns in this domain including, but not limited to: inadequate knowledge of medication side effects, addiction and tolerance; timing of administration, dosage and titration of dosage to treat increasing symptoms. To counter these problems, evaluation of medication use by health professionals and increased verbal and written information in line with caregiver need enhances understanding (Docherty et al. 2008).

Kristjanson et al. (2003) report that the most useful ways for nurses to assist families in providing comfort care at home are to educate them about basic pain management principles and skills; advocate for the patient and family to ensure their pain management needs are met; and to act as a consultant to the family.

With regards to more general **information needs**, Milne and Quinn (2009) state that information is required in relation to treatment side effects; what will happen in the future, symptoms of the disease, availability of community resources, and the state of the patient's illness. Providing carers with information in a variety of modalities (verbal, written, audio) allows them to understand the expected course of the illness, thereby relieving some of their uncertainty, as well as enabling them to provide the required care. Kristjanson et al. (2003) elaborate further by stressing that provision of practical

information helps families anticipate the next steps of the person's illness and decreases the chance that they will be caught in a moment of crisis, unprepared for a deterioration in the person's condition.

The *Guidelines for a Palliative Approach for Aged Care in a Community Setting* (2011) specify that family carers of people who have life-limiting illness would like information about:

- the caring role and its boundaries (Lee et al. 2001)
- the cause of the disease (Osse et al. 2006)
- physical problems that can be expected (Osse et al. 2006)
- possibilities of treatment and side effects (Osse et al. 2006)
- alternative healing methods (Osse et al. 2006)
- skills needed to meet the daily demands of caring (Osse et al. 2006)
- how to provide nourishment (Osse et al. 2006)
- behavioural management and functional issues, when the care recipient has dementia (Gonzalez-Salvador et al. 1999)
- what will happen in the future (that is, life expectancy and service availability) (Casarett et al. 2003, Osse et al. 2006)
- symptoms and how they can be managed (Casarett et al. 2003)
- death (Casarett et al. 2003).

In the *Guidelines for a Palliative Approach for Aged Care in a Community Setting* (the 'Guidelines') published in 2011 by the Australian Government Department of Health and Ageing and approved by the National Health and Medical Research Council, the efficacy of various disease-specific education programs for carers of palliative care patients with specified diseases is examined.

Disease-specific education for carers is defined in the Guidelines as education about the disease and its symptoms, rather than just about how to deal with the stresses of providing care. It may involve only the provision of information, or an approach that also shows or explains to the carer how to apply that information (active education). Skills training or counselling are two of the approaches that may help carers apply disease-specific information when they are providing care.

The Guidelines found high level evidence for the provision of disease specific information (in an active education format) to improve a variety of carer outcomes for:

- carers of older adults with advanced cancer
- carers of older adults who have moderate or severe dementia
- carers of adults who have advanced frailty or disability due to stroke.

In a study by Grbich et al. (2001) caregivers nominated the following ways to improve access to information, including:

- videos, available at diagnosis in a range of languages, covering topics such as: 'What is palliative care?', 'What to expect', 'Services available' and 'Manual handling techniques'
- a regular check by health professionals regarding how much information caregivers have and what they might need to know at that point
- a folder of services — especially those likely to be needed during the last stages, including night services, and with details of any costs involved
- a list of equipment with illustrations and information on where to get these items and how to use them.

A systematic literature review of the self-reported unmet needs of patients and carers by Ventura et al. (2014) found that patients and carers wanted more information about the illness, often about managing their lives and making decisions, and how the condition would progress. Patients were particularly concerned about what would happen to their partner when they died and precisely when they would die. Carers required more information about what to do at the time of the patient's death. Carers also expressed that they would like to be given information in writing and a need for more information about their caregiving role. For example, they wanted information about skills to manage patient symptoms so that they would feel more competent as a care provider. They also wanted information about alternative medicines and euthanasia.

With regards to **practical care** needs, this refers to information on how to move and toilet the patient, how to provide basic hygiene (such as mouth care) and how to attend to skin care. Other practical care needs such as transport to and from appointments, financial assistance and access to respite services are other forms of practical assistance that fall under this category (Kristjanson et al. 2003).

For example, the Loddon Mallee Regional Palliative Care Consortium (*Annual Report 2013–14*) has produced a written resource for carers ('information cards') of palliative care patients to assist them when caring at home. The kit was produced with clinician and carer input. Carers are shown face to face how to use the equipment by a nurse, physiotherapist or occupational therapist and the information cards are given to carers to refer to once staff have finished demonstrating use of the relevant equipment. The kit includes sixteen information and equipment cards covering topics such as how to use a:

- bath chair
- bath board
- commode
- shower stool
- bed pole
- home oxygen concentrator
- portable oxygen concentrator
- portable nebuliser.

Other topics covered include helping a person get into and out of a car safely; helping a person to walk safely; how to push a person in a wheelchair; how to prevent bed sores; and what to do when death has occurred.

In a qualitative study examining the information and support needs of family carers at the end of-life, Harrop et al. (2014) suggest a more nuanced approach to carer education whereby certain topics (such as diet, personal hygiene, manual handling, respite, the roles of different health and support services, and advice on carer benefits) could be provided as part of a general or universal carer information resource, whereas other more complex topics such as medication, symptom management, information on illness progression and the dying process would require tailored information to be delivered by health professionals according to the needs of each individual family.

The authors go on to argue that the cost of developing such a carer resource combined with appropriate training for health care staff in delivering the more complex information is potentially cheaper than the cost of hospital readmission following the breakdown of family care.

**Emotional support** includes providing support with coping with loss, uncertainty about the illness, impending death, communication within the family, and psychological distress. Interventions most helpful to families under this domain include helping families to:

- identify ways of coping (for example, taking one day at a time, use of social support, seeking information to dispel uncertainty, knowing how to compartmentalise concerns)
- identify positive aspects of caregiving role
- identify ways of caring for themselves, avoiding caregiver fatigue
- acknowledge importance of family members' emotional needs (Kristjanson et al. 2003).

In 2010, the Centre for Palliative Care developed clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. Good and/or high quality evidence was found for the following psychosocial interventions:

- enhancing problem solving or coping through sessions on planning, creativity, optimism and information
- provision of psycho-educational support to prepare family caregivers for their role through home visits and phone calls
- individual and family counselling as well as weekly caregiver support groups
- partner-guided pain management training
- teaching caregivers behaviour strategies to improve their sleep.
- group psycho-education programs to prepare family caregivers for their role.

The clinical practice guidelines also recognise the importance of assessing caregivers at risk of poor psychological health and/or prolonged grief and to plan relevant interventions.

Ventura et al. (2014) also identify psychosocial and spiritual needs as important for patients and carers. These included support in dealing with worries, fear of suffering and death and coping with an unpredictable future.

Examples of more comprehensive lists of carer support strategies include those detailed by Stajduhar and Cohen (2009) and Panke and Ferrell (2010), as reproduced below.

Carers' needs that must be satisfied in order to prevent problems from occurring, are summarised below:

**Physical:**

- strength to transfer the patient from bed to chair, and to lift and turn the patient in bed
- adequate sleep
- appetising food and protected time and atmosphere to eat properly
- safety and security in the home, for both the patient and the carer
- practical support with, for example, providing care to the patient, transportation of the patient, special meal preparation, doing extra laundry etc
- education regarding safe procedures for caring for the patient; for example, lifting, transferring, changing bed sheets, hygienic practices etc.

***Psycho-social:***

- psychologically adapt to providing intimate care for the patient, which may be especially difficult for children of the opposite sex caring for a parent
- recognition of their efforts and experience by family and friends
- supports to prevent social isolation
- assistance in dealing with past strongly negative experiences with the patient; for example, abuse
- conflict resolution, where family or patient's quality of life is impaired
- privacy with spouse and children if the patient is neither of these
- prevention and/or early treatment for depression and anxiety
- time to adapt to the role of carer — since the role is often changing rapidly, this should be considered an ongoing process, with extra help available as the carer adjusts to new circumstances.

***Cognitive:***

- assistance in preparing for complex cognitive tasks, such as organising healthcare, patient treatments at home, complex medication administration;
- mental breaks and respite from the illness, and, for some, from the patient
- recognition that cognitive problems can arise from extreme fatigue.

***Formal/informal support:***

- acknowledging the carer's primary concern that they will suffer if the patient is suffering
- acknowledging that carers who evaluate the patient's healthcare as worse are more often depressed
- effective communication and continuity of care from both within the healthcare system and from family and friends
- helping the carer to ask for help, and how to organise help most effectively.

From Stajduhar and Cohen (2009) in Hudson and Payne (2009)

Suggested interventions to facilitate family coping with an advanced illness are illustrated below:

**1. Communication:** Assess family communication patterns prior to and over the course of an illness.

**2. Family relationships:** Acknowledge the relationship of the family member to the patient. Caregiving is significantly influenced by the distinct relationship (i.e. spouse, parent, child).

**3. Family developmental level:** Recognize the family's developmental level and its relationship to their coping with the illness. Family developmental crises (recent retirement, births, marriages etc) influence coping with illness. Assess whether multiple developmental crises are occurring.

**4. Family conferences:** Establish mechanisms for conducting family conferences to facilitate shared communication between patient, family and health care providers and to clarify changing goals of care.

**5. Concurrent stressors:** Recognize areas of concurrent stress which may be unrelated to the patient or the illness (i.e. job loss, stress in the extended family, coping with children).

**6. Financial concerns:** Provide counselling for the direct and indirect financial burdens associated with chronic illness.

**7. Education:** Diminish caregiver's sense of helplessness by empowering them with knowledge and skills to enhance patient comfort (i.e. use of drug and non-drug modalities).

**8. Pain education:** Provide structured pain education to defuse anxiety regarding issues such as addiction and tolerance.

**9. Physical aspects of care:** Develop family education regarding the basic physical aspects of care (i.e. lifting, bathing, toileting).

**10. Encourage expression of fears and concerns:** Provide opportunities for family caregivers to express their emotions through individual or group support away from the patient.

**11. Emotional strain:** Provide opportunities to verbalize the emotional strain inherent in caregiving during terminal illness.

**12. Risk for dysfunctional coping:** Identify families at risk for dysfunctional coping with terminal illness. Risk factors include families with poor communication patterns, prior history of family stress, and those with prior issues of non-compliance.

**13. Issues of uncertainty:** Provide information regarding anticipated symptoms and discuss the distress associated with uncertainty.

**14. The actual death:** Provide information regarding what to expect with the actual death event

**15. Sources of family support:** Evaluate and coordinate available sources of family support; i.e. social workers, spiritual support persons, clinical psychologists, psychiatrists, family counselling, peer support groups.

From Panke and Ferrell (2010)

In addition, Hudson and Hudson (2012) have produced a comprehensive guidebook for family carers of people diagnosed with a life-threatening illness who require palliative care. It was developed following a comprehensive literature review, input from senior clinicians and academics, and input from current and past carers of people with a life-threatening illness in need of palliative care. It offers advice to carers on myriad relevant topics, such as: self-care; caring for relationships; supports available to carers; practical care tips (that is, dealing with common symptoms experienced by people who need palliative care); planning for the future (that is, advance care planning; preparing a will; powers of attorney; funeral planning); care as death approaches; and bereavement.

## 13. Systematic reviews of carer interventions

A recent Cochrane Collaboration review of interventions (based on eleven RCTs involving 1836 caregiver participants) designed to support informal caregivers of patients in the terminal phase of a disease found that there is low quality evidence that interventions directly supporting the caregiver significantly reduce psychological distress in the short term and that they may marginally improve coping skills and quality of life, but neither of these results were statistically significant for these two outcomes (Candy et al. 2011).

Evidence was less clear on indirect interventions (that is, those that aim to support caregivers indirectly via patient care). While both trials in this category found that supporting the patient may reduce psychological distress, the results were not statistically significant (Candy et al. 2011).

In a systematic literature review into the best ways to help caregivers in cancer and palliative care, Harding and Higginson (2003) assessed the effectiveness of home care nursing, one-to-one interventions and group work interventions. With respect to home care nursing services, they noted the high levels of satisfaction with such services, but cautioned that due to the high levels of psychological

morbidity in carers using such services, it appears that generic supportive nursing care does not meet all of carers' needs.

With respect to one-to-one interventions that provide support, education and build problem-solving skills, they found that these interventions are time consuming and costly, and such psychological and/or individual based services may prove unacceptable to many carers.

With respect to group interventions, it was noted that they are widely suggested as an appropriate format to deliver the necessary support and information to carers, and have been used successfully in this way for cancer patients. However, the authors called for research into the effectiveness of group interventions, in particular in relation to their format and optimum length.

In a systematic review examining the effectiveness of psychosocial interventions for informal cancer caregivers, Applebaum and Breitbart (2013) found that interventions consisting of multiple components or genres, rather than those just focusing on one dimension of need (for example, communication training for couples combined with information on cancer treatment, side effects and symptom management) provided the best results in terms of treatment effect. Generally speaking, psychoeducational interventions and problem solving / skills building interventions were found to increase caregivers' knowledge base and ability to provide care — such as assessing and managing patients' symptoms and enhancing caregiver's overall coping ability. One limitation of the Applebaum et al.'s review is that it included interventions across the entire cancer trajectory, hence was not specific to caregivers providing care in the 'palliative' phase of cancer.

In a similar vein, Northouse et al. (2010) conducted a meta-analysis examining interventions with family caregivers of cancer patients. At a broad level, the authors concluded that although psychoeducational, skills training and therapeutic counselling interventions had small to medium effects, they nevertheless reduced caregiver burden, improved aspects of their quality of life and improved coping ability and self-efficacy.

The majority of the interventions included material that covered caring for the patient as well as self-care for the caregiver, together with maintaining family and marital relationships. The majority of the interventions were delivered jointly to patients and family caregivers. The authors pointed out that there was wide variation in the intervention dose (ranging from two to 12 sessions) and intervention duration (ranging from several days to 18 months), and argued for greater focus on both these elements in the future so that there is greater precision in determining effective interventions.

In summary, Northouse et al. (2010) argue that for the patient to receive optimal care, the mental and physical health of carers needs to be addressed. Programs directed solely at patients are inadequate at meeting their needs because the patient's care depends substantially on family caregivers.

## 14. Communication between health professionals and families

Effective communication between health professionals and families has also been identified as an important caregiver need. Family members need to feel confident that the patient's comfort, needs and perceptions of symptoms are attended to, requiring liberal amounts of information about the disease and treatment, provided in a way that they can process and at a pace that is comfortable to them. Caregivers also benefit from information about diagnosis, prognosis, treatment options and expected course of recovery to help lessen their fears and increase their sense of predictability (Aoun et al. 2005). Continuing this theme, Ventura et al. (2014) found that communication problems in consultations with doctors were also reported as an issue warranting attention, as patients and carers believed that they

were not being listened to. They also reported that the doctors were not interested in them or had enough time to listen to their concerns and that they were often unfamiliar with the current concerns of the patient.

In a randomised controlled trial to assess the efficacy of a psycho-educational intervention for primary caregivers of cancer patients dying at home, primary caregivers reported that the most challenging aspects of their role related to inadequate health professional support (Hudson et al. 2004, cited in Palliative Care Australia 2004). Approximately one-quarter of caregivers were disturbed by poor continuity, inadequate information, limited respite, lack of symptom management education and health professional role-related issues. This research further found that most caregivers, if given the opportunity, were willing to talk about issues specific to their needs and concerns, and they chose to be interviewed without the presence of their care recipient, thus emphasising the importance of more structured approaches to family care.

Open communication between health professionals themselves is also important, or else patients can form the belief that services are poorly coordinated (Ventura et al. 2014)

## 15. Practice recommendations

Based on this review of the carer support literature, a number of recommendations have been put forward to improve the outcomes of caregivers of patients with a life-limiting illness / receiving palliative care.

Harding and Higginson (2003) state that practitioners planning to develop interventions for carers must:

- ensure that their service is theory based
- focus specifically on the needs of carers (that is, not a generic service)
- address issues of access and acceptability in the initial stages
- have clear and modest aims (which should not necessarily be multidimensional)
- ensure that these aims are evaluated using rigorous evaluation methods (using repeated measures from baseline and employ comparison groups).

Palliative care services also need to be aware of the barriers faced by caregivers in accessing support and to seek to overcome these barriers where possible and appropriate. The *Guidelines for a Palliative Approach for Aged Care in a Community Setting* (2011) state that some family carers do not use support services even when they need them due to the following reasons:

- concerns about privacy and confidentiality, especially in rural and remote areas (Li 2006)
- difficulty in accessing services because of the distance and travelling required; for example, to take an older person to a day respite centre (Li 2006)
- lack of awareness of community services or finding them inadequate (Strain and Blandford 2002; Teno et al. 2004)
- the belief that it is inappropriate to use services (this belief may be cultural) (Brazil et al. 2005)
- a wish to maintain their relationship with the older person (Brazil et al. 2005)
- expense of services, or the lack of availability of local services, especially in rural or remote areas (Cravens et al. 2005, Li 2006)

- challenges experienced with managing a change in routine because of service delivery, especially if the older person has cognitive impairment (Strain and Blandford 2002).

Service providers also need to focus on the support needs of the extended support network so that the terminally ill patient can remain at home for as long as possible, if that is what they desire. This issue has been the focus of inquiry by Burns et al. (2013), who found that extended family members (not first-degree relatives) and friends accounted for more than half of identified hands-on caregivers, and that people with extended family or friends providing care were much more likely to be supported to die at home compared to having a spousal carer.

## 16. Knowledge translation/implementation science

This literature review has attempted to document the existing evidence base for interventions to support carers looking after people with life-limiting illnesses.

However, documentation of the existing evidence base is only one part of the jigsaw. Tellingly, in a monograph examining the relationship between evidence based practice and its implementation in human service systems, Fixsen et al. (2005) point out that ‘...all the paper in file cabinets plus all the manuals on the shelves do not equal real-world transformation of human service systems through innovative practice. While paperwork and manuals do represent what is known about effective interventions, these tools are not being used effectively to achieve behavioural health outcomes for children, families, and adults nationally’ (p. vi).

There are a number of definitions of knowledge translation. For the purposes of increasing the quality of palliative care delivered to clients and carers, the following definition seems apt:

[Knowledge translation is]...the effective and timely incorporation of evidence-based information into the practices of health professionals in such a way as to effect optimal health care outcomes and maximize the potential of the health system (Knowledge Translation Program, Faculty of Medicine, University of Toronto (2004), cited in Fixsen et al. 2005).

Kutner (2011) recognises the importance of dissemination and implementation research in palliative care.

‘It is time for palliative care, as a field, to equally prioritize rigorously studying the most effective ways of disseminating and implementing existing evidence into practice and generating new evidence.

For those areas in which there is not yet sufficient evidence, we must design efficacy and effectiveness trials for dissemination and implementation, building in from the beginning study elements that facilitate the rapid translation of evidence into practice. We have a moral imperative to do so. Dissemination and implementation of evidence into practice is necessary to achieve a return on investment in our research enterprise and to positively affect outcomes in a broader population. We must conduct dissemination and implementation trials that are rigorous, relevant, and practical. We have to effectively get our existing evidence out into practice as soon as we can; our patients and their families don’t have the time to wait.’

This literature review has uncovered a substantial amount of information on meeting the needs of caregivers of people suffering from a terminal illness. Much is known about what should be provided, although many authors question the methodological robustness of the evidence base. This raises the question of whether service providers should put into action those interventions that have been described to be effective in 'lower' quality studies.

On the other hand, it is unrealistic to expect service providers to do nothing in light of imperfect evidence. In fact, it would not be surprising for providers to rely on expert consensus and 'practice wisdom' for a significant amount of their practice, in circumstances where the research evidence is either lacking or contradictory.

This is not to say that **everything** is known about how to support carers looking after someone with a terminal illness. There are many aspects of providing carer support which remain under-researched (for example, psychosocial and bereavement support for carers) or where extra details are required in order to understand the most appropriate carer support interventions and dose-response profiles. This need is brought into sharp focus by the establishment of the International Palliative Care Family Carer Research Collaboration in 2006, whose stated aim is to 'improve evidence based support provided to family carers of palliative care patients'. Eagar et al. (2007) state that 'little is known about the effective 'dose' of carer support interventions or the best time for their delivery'. It is also noteworthy that a scan of the literature reveals that a lot is already known about how to support carers of terminally ill patients, and yet at the same time, there are many articles that lament the shortage of evidence-based strategies to support family carers.

Hudson (2013) makes the salient observation that guidelines and standards regarding carer support have been published but the extent of their implementation is unknown and he calls for academics, clinicians and policymakers to rigorously explore ways of disseminating and implementing new evidence. Knowledge implementation/knowledge translation is a field of scientific inquiry in its own right and the department needs to be mindful of choosing the best approaches to put the best available palliative care evidence into practice. Fixsen et al. (2005) come to the conclusion that inadequate attention has been paid to translate scientific knowledge into human service systems.

Fixsen et al. (2005) further argue that it is important to give as much attention to the development and measurement of implementation practices as is given to intervention practices so that intervention effectiveness problems can be differentiated from implementation effectiveness problems, remembering that strategies to address implementation problems will be different from strategies to address the ineffectiveness of the intervention itself.

Some pointers to **ineffective** knowledge implementation strategies are given by Fixsen et al. (2005).

They state that:

- information dissemination alone (research literature, mailings, promulgation of practice guidelines) is an ineffective implementation method
- training (no matter how well done) by itself is an ineffective implementation method.

In an analysis of 18 systematic reviews that investigated the effectiveness of dissemination and implementation strategies of research findings, Bero et al. (1998, cited in Sudsawad 2007) found that:

- most of the reviews reported modest improvements in performance after interventions
- passive dissemination of information was generally ineffective in altering practices, no matter how important the issue or how valid the assessment methods
- multifaceted interventions, a combination of methods including two or more interventions, seemed to be more effective than single interventions.

In an updated version of the Bero et al. overview (1998), Grimshaw et al. (2001, cited in Sudsawad P 2007) conducted an overview of 41 systematic reviews published between 1989 and 1998 to examine the effectiveness of intervention strategies in changing providers' behaviour to improve quality of care and found that passive approaches are ineffective and unlikely to result in behaviour change (although they could be useful in raising awareness); whereas multifaceted interventions that targeted several barriers to change are more likely to be effective than single interventions.

Audit and feedback and use of local opinion leaders were variably effective; whereas the interventions that were generally effective included educational outreach and reminders. However, most of the interventions were effective under some circumstances, and none was effective under all circumstances.

At a systems level, Grimshaw et al. (2012) caution that 'while better knowledge management is necessary, it is unlikely by itself to be sufficient to ensure knowledge translation because of barriers working at different levels of healthcare systems, many of which operate at levels beyond the control of an individual practitioner. For example, barriers may operate at other levels of a healthcare system including: structural barriers (e.g. financial disincentives), organizational barriers (e.g. inappropriate skill mix, lack of facilities or equipment), peer group barriers (e.g. local standards of care not in line with desired practice), professional (e.g. knowledge, attitudes and skills) and professional-patient interaction barriers (e.g. communication and information processing issues)'.

Eagar et al. (2007) argue that there needs to be stronger linkages between the practitioner and research communities to facilitate translation of research into practice. In a workshop on the subject 'effective caring' hosted by the University of Wollongong in 2007 attended by key service delivery and academic experts, workshop participants recommended the involvement of service providers in the design of large trials, so they can provide input on whether the proposed intervention is feasible and could be implemented.

Related to the above, aggregating lessons from pilot projects was seen as a promising approach for developing an evidence base around current practice. Researchers could work with service providers to help define what they want to achieve and identify outcome indicators and a range of valid, reliable and easy-to-use evaluation tools. In order for evaluation questions to 'line up' across studies, it would be necessary to agree first on a set of key outcome measures.

Another recommended strategy was the provision of sufficient resources for a well-managed rollout of evidence-informed practice in the field. The Department could play a central role in this process of bringing practitioners and researchers together (Eagar et al. 2007).

The same authors also argue for building a stronger research culture in the carer support sector by encouraging the use of common tools for evaluation so that local lessons can be easily shared with others and making small grants available to services so that they can evaluate themselves.

Having regard to what is already known about knowledge translation, the key challenge for the department is how best to ensure the systematic uptake and implementation of what is currently accepted as best practice with respect to carer support across all specialist palliative care services.

And related to this, how do we ensure systematic uptake of new evidence in relation to carer support interventions? In addition, does the department have a role in funding and shaping carer support research to address knowledge gaps?

The department has a number of established mechanisms it uses to facilitate the translation of research into practice, as described below.

One of the key mechanisms relevant to clinical service improvement is the work of the Endorsement Standing Sub-committee (ESSC) of the PCCN. Its role is to coordinate the progression of local strategies and clinical documents to the PCCN for translation into state-based clinical practice improvements. The role of the PCCN is to promote consistency of practice across the state. Endorsed documents are recommended for use by the palliative care field statewide but not necessarily mandated.

ESSC has developed a transparent and fair process for ensuring documents submitted undergo a formal assessment that ensures all clinical guidance documents are evidence based and meet agreed criteria related to statewide relevance, across setting applicability, and the support of the relevant regional palliative care consortium. The process includes provision of informed advice to the PCCN and the department regarding final endorsement of guidance documents and their ongoing review.

While nothing in the carer support space has currently been endorsed, this mechanism can be used for the review of carer support strategies at a local level which have the potential to be adopted as statewide practices through the ESSC process.

Documents submitted to the ESSC are required to meet the following criteria, as detailed in the box below.

- Process for seeking ESSC endorsement of clinical documents**
1. That the document has relevance to palliative care at a statewide level.
  2. That the document is applicable across a variety of settings. Documents must be relevant to the clinical settings of palliative care inpatient, community, and consultancy services. If documents predominantly relate to another clinical setting for example, renal, cardiac, etc, the submitting author should provide evidence that the document is supported by that network. The author may also request the document be considered by both networks collaboratively.
  3. That the document has relevance to one or more disciplines traditionally providing palliative care for example, medicine, nursing, social work, pastoral care, psychology, etc.
  4. There is a strong preference that the document is submitted through the regional consortia prior to submission to ESSC. This will not apply for statewide programs. Submissions by an individual will not be accepted.
  5. That there is evidence of a literature review with appropriate referencing and documentation of the level(s) of evidence the submitted documents present (according to the National Health & Medical Research Council) — see Attachment 1. A comprehensive search of other organisational or clearing house portals is demonstrated. For example CareSearch and the National Institute of Clinical Studies Clinical Guidelines portal may have existing endorsed relevant documents.
  6. That the document has been developed or produced by public or private health organisations; non-government or government agencies; palliative care consortia; peak bodies and/or relevant professional organisations/societies.
  7. That the document meets the relevant organisational quality processes and/or ethics approvals. For example, it is expected that a document including pharmacological information would be reviewed by the organisation’s pharmacy committee.
  8. That two organisational/agency contacts are provided for current and future reference. This contact information will be used to notify of endorsement; seek further information prior to endorsement; for ongoing accuracy and relevance during the period of endorsement; and to review, update and re-submit the document at the conclusion of the endorsement period.
  9. That the document has background information that includes the context and scope for this particular clinical guidance document. This may also include specific limitations or exclusions.

Another avenue of knowledge dissemination relies on consortia representatives of the Palliative Care Clinical Network (PCCN) passing on relevant information related to clinical service improvement as discussed by the PCCN to their clinical advisory group and then filtering down to individual health services.

This function is enshrined in the palliative care consortium role statement, which states that ‘in conjunction with the PCCN, [the role of the Consortium is to] implement the service delivery framework, and undertake communication, capacity building and clinical service improvement initiatives’. The role of the PCCN in facilitating clinical service improvement is assisted by each consortium’s clinical practitioners group whose role is ‘to ensure decisions made by the consortium are based on evidence-based clinical practice and develop (or source) and help implement resources that promote evidence-based clinical practice’.

Of course, this is not to deny that there are other ways that health care professionals can obtain access to the latest evidence to inform and guide their practice (that is, subscription to professional journals, membership of professional organisations, professional networking, conferences, national clearing houses on palliative care such as the Caresearch website funded by the Australian Government Department of Health, the Centre for Palliative Care website and so on), nor is it correct to say that the PCCN is the font of all clinical knowledge when it comes to specialist palliative care. To rely on the PCCN to disseminate all evidence-based knowledge is beyond its current scope and resourcing.

However, it is true to say that the majority of information dissemination from the department relies on passive dissemination, which, going by the published literature, is generally ineffective in changing practices. This however, goes against the weight of evidence that suggests that multifaceted interventions are more effective than relying on passive intervention strategies to change practice.

Putting to one side the adequacy of resourcing, the department has a number of mechanisms at its disposal to facilitate the implementation of evidence into practice. For example, it could:

- use the authority and combined professional expertise of the Palliative Care Clinical Network to disseminate best practice about caring for carers of people with a terminal illness to all palliative care consortia and then have that information filtered down to Clinical Advisory Groups for action within individual health services
- develop palliative care carer support guidelines (based on evidence from the latest research) to be inserted into the *Victorian health policy and funding guidelines*, which will signal to palliative care services the department’s expectations of what carers of people with terminal illnesses can be expected to receive. Non-government providers of palliative care services will be covered by the Whole of Victorian Government Common Funding agreement if the *Victorian health policy and funding guidelines* are referenced
- insert palliative care carer support requirements into the annual statement of priorities agreement between the Minister/Secretary and health services
- fund the Centre for Palliative Care to proactively support health services support carers of terminally ill patients, acknowledging that much of this information is already published on the Centre for Palliative Care website and that there are separate resources for health professionals and patients/carers
- fund the Centre for Palliative Care to partner with specialist palliative care providers to evaluate existing carer support interventions and design a methodology for piloting and evaluating planned interventions
- review the results of the environmental scan and compare it with best practice service provision
- identify examples of good work and widely disseminate it through the PCCN and through the PCCN to consortia, and then through consortia Clinical Advisory Groups to individual health services.

## 17. Conclusion and recommendations for further work

After reviewing the available literature on the efficacy of respite in improving caregiver and patient outcomes, it was found that there were limited rigorous intervention studies supporting its efficacy, although there was more support for its efficacy in quasi-experimental and/or descriptive studies.

As a result, the scope of the literature review was widened to include a broader review of caregiver interventions (not just respite alone) intended to improve caregiver and patient outcomes for people receiving palliative care.

The review uncovered a substantial amount of information on meeting the needs of caregivers of people suffering from a terminal illness. Much is known about what should be provided, although many authors question the methodological robustness of the evidence base.

To move forward, it is recommended that a tailored environmental scan/survey be distributed to specialist palliative care providers for completion in order to facilitate further policy development in this area. This is because there is hardly any current documented evidence available to the department which provides detail on which providers offer which types of respite (in-home, in-hospital, centre based) or other forms of carer support, how they target clients in most need or what outcomes are achieved for clients of respite services and other forms of carer support and how these outcomes are measured. The survey could be structured in such a way as to incorporate the best practice approaches identified in the literature review to determine which services already adopt best practice approaches and what the gaps are with a view to remodelling respite services and other carer support services in line with best practice.

In a study of service preferences among family caregivers of the terminally ill in Canada (Brazil et al. 2005), the five most requested support services were housekeeping, respite, in-home nursing, personal support workers and self-help groups.

As a first step to configuring an appropriate service system, it would also seem logical to determine service preferences among caregivers of the terminally ill in Victoria. The department already captured much of this information in the questions posed through the Victorian Palliative Care Satisfaction Survey (VPCSS), which also substantially addressed the relevant categories of carers' needs as documented in the palliative care literature. The contract for the conduct of the VPCSS expired in June 2014. At the time of writing, the department is in the process of deciding how the needs of carers of people with a terminal illness will be measured. Whilst the specifics are not yet known, in line with developments in the field of 'patient satisfaction', in the future the department will be moving to an assessment of patient experience rather than solely focusing on satisfaction, as such an approach fails to capture significant information about the delivery process and quality of the service received, which hinders quality improvement. For example, client and carer satisfaction has been continually high across the palliative care sector, yet it is reasonable to expect that a client may still have experienced service delivery problems at some point in their care. Identifying these experiences offers areas for further improvement.

Satisfaction surveys focus on one aspect of the client's experience and may not adequately represent the aspects most relevant to the client along their entire journey. In contrast, experience measures ask clients and/or carers to comment on the occurrence of certain events and processes, rather than how satisfied they were with the overall episode of care.

Questions that are focused on satisfaction can fail to provide specific information that can be applied to quality improvement processes. In contrast, experience questions seek factual responses regarding what may or may not have happened during an episode of care, providing information that can be directly applied.

Notwithstanding the above, there is a clear opportunity to investigate the nature of caregiver needs and preferences in greater depth. This is because the VPCSS only provided summary level information on some of the domains of caregiver need. Therefore, the proposed environmental scan will allow the department to get a more comprehensive understanding of the nature of support provided to carers of palliative care patients, with a view to reshaping the service system so that it better meets the needs of carers.

With respect to delivering the most effective and appropriate caregiver interventions at the right time, Payne et al. (1999) point out that different disease trajectories are likely to have a major impact on the levels of caregiver stress. This theme was repeated by Pasacreta and McCorkle (2000, cited in Palliative Care Australia 2004) and McCorkle and Pasacreta (2001, cited in Palliative Care Australia 2004) in a review of cancer care literature specific to caregiver interventions. They recommended testing caregiver interventions over time with homogeneous groups of patients at specific points on the illness trajectory (trajectory onset, crisis, acute, stable, unstable, downward and dying). They posit that some interventions could be most effective at certain points in the illness trajectory while others could be preventive across several stages.

Instead of just focusing on respite, it is suggested that a more fruitful strategy would be to understand the most effective **package of services** that benefit caregivers in their role of supporting palliative care patients. Using Pasacreta and McCorkle's framework may be an appropriate way of designing a targeted package of interventions at the right time and at the appropriate point in the palliative care journey to both carers and patients to improve quality of life for both parties and increase the chances of the patient dying in their place of choice. This is an ideal that the palliative care system should be aiming for. However, it is noteworthy that there were no studies or systematic reviews reviewed as part of this piece of work that have attempted to test the utility of McCorkle and Pasacreta's model.

Another key challenge is to determine how best to implement best practice research evidence into day-to-day service delivery on a systematic basis. This needs to be informed by the latest research on implementation science. The department, through the environmental scan, will seek sector input to inform the most appropriate way to move forward on this issue.

This literature review and the proposed environmental scan of specialist palliative care providers in Victoria represents an important step in understanding what carers need and when and will facilitate further ongoing research to fill the gaps in our knowledge of how to support caregivers of the terminally ill.

The ultimate aim would be to construct a palliative care service system that provides the optimum mix and quantum of interventions and/or services to carers, and in so doing, maintains their resilience and ability to continue in their caring role for as long as reasonably feasible.

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