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Loss and grief in the workplace
What can we learn from the literature?
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Abstract
Purpose – The purpose of this paper is to determine how Australian workplaces, their managers and
employees respond to those who are grieving at work, as a result of chronic or terminal illness, or caring for
those with chronic or terminal illness. The review draws on Australian and relevant international literature and
seeks to answer this question.
Design/methodology/approach – A literature review was undertaken in preparation for an Australian study
examining workplace supports for people who are grieving – because they are carers, have experienced a
death, or are balancing their own illness with their work. Using a range of search terms, the literature was
searched for relevant work between 1980 and 2010. The search found examples of workplace supports
throughout the world and some developing Australian literature.
Findings – Despite illness and death occurring at any stage of a person’s life, there is little research that
identifies workplace issues associated with grief and loss. And while workplace legislation allows for minimal
supports, there was evidence that some workplaces have begun to offer flexibility for work life balance.
Practical implications – Effective workplace supports will involve individual and workplace responses, but also
require legislative approaches in order to effect broad-based system change.
Originality/value – The paper compares Australian and international literature about workplace supports and
provides an overview of the issues arising.
Keywords Death, Workplace, Business policy, Quality of life, Interpersonal relations, Australia

Paper type Literature review

Introduction
When people are grieving, every aspect of their life is affected – including their work life. To date, little
research has been done to assist in identifying the issues associated with grief and loss in the workplace even
though illness or death, the major causes of grief, can touch a person at any stage of their life.
Australia has an ageing population and a shrinking workforce. As a result it is likely that more Australian
workers will come into contact with illness or grief in the workplace, whether it is their own, a work colleague’s
or someone for whom they are caring (such as a family member or close friend). A worker may be grieving
because they have experienced a death through their work, or when coping with one’s own or a colleague’s
illness. Vickers (2009) suggests that the concept that grief exists in and around the workplace is often not
recognised. Whilst some workplaces accept the need to offer flexibility for work life balance, there seems to be
little organisational support available for the specific needs associated with the state of grieving. In response
to this identified need, to assist employees and colleagues to better understand and/or manage the needs of
grieving individuals, a workplace support model has been proposed (Bottomley and Tehan, 2005; Tehan,
2006).
This paper describes the literature that was reviewed in the development of a workplace support model
(Tehan, 2006), as well as a search for more recently published literature. The literature review indicated that
little research relating to the impact of grief in the workplace had been undertaken in Australia and that policy
and procedures related to workplace grief vary from organisation to organisation. There are, however, many
ad hoc examples of how some organisations support staff that are grappling with illness issues and the
associated loss and grief they may be experiencing.

Objectives and methods
The purpose of this literature review is to determine how Australian workplaces, their managers and
employees respond to those who are grieving at work, as a result of chronic or terminal illness, or caring for
those with chronic or terminal illness. The review draws on Australian and relevant international literature and seeks to answer this question based on:

- evidence of any previous studies relating to research about workplace support needs for grieving people; and
- key messages from previous research and relevant secondary sources, including reasoned argument and legislation.

Our literature search commenced with the broad phrase: “life-threatening” rather than “terminal illness”, to pick up any literature more likely to describe the needs of people in the early stages of their illness. The search terms used also included literature about people “living with a life-threatening illness” or “with serious chronic illness”, because most people live in hope that their illness will be cured. As the review of the literature was the forerunner to the development of a workplace support model we were also interested in workplace health promotion, management and employer issues, employed and bereaved carer issues, the role of general practitioners and any available employer supports. There was no restriction on workplace size or ownership, with public and private sectors and small, medium and large workplaces all included. The search included both the Australian and international literature.

An electronic literature search was undertaken (from 1980 to 2010) using the databases of Cinahl, Google, Emonet Resource Net and CareSearch. A list of search terms used was quite broad and in some cases highlighted the Australian context (especially around the workplace policy context). Search terms included palliative care and palliative approach; caregiver and carer; grief and bereavement; death education; work, workplace policy, workplace supports and human resource management; and their synonyms were used to search for relevant reports. Not being a systematic review, but wanting to ascertain issues of workplace loss and grief, we sought to capture relevant literature especially on policy, as well research-based articles.

Findings

The search terms above identified a large number of articles published in both academic journals and “grey” literature from 1980 to 2010. The grey literature refers to policy documents, working papers, and community materials that are not commercially published. Abstract review found that most of the literature was descriptive and related to broadly identified issues about life threatening illness and associated loss and grief in the workplace. Some described workplace supports but few studies reported actual results of workplace-based trials, cohort studies or case studies. From the review of abstracts we identified 47 papers that were likely to be relevant to the development of workplace supports as they provided some evidence of the impact of grief in the workplace on employees, managers or employers (including confidentiality, discrimination and economic), or workplace support policies and procedures to support people with illness or those providing care. Of the 47 papers reviewed, only 14 were Australian.

The literature was grouped according to a range of key issues and then into themes to form a framework to support the development of a “workplace support model”.

These themes were:

- grief, loss and bereavement: an Occupational Health & Safety (OH&S) issue;
- the economic impact of inadequate workplace support;
- stigma and discrimination attached to illness;
- boundaries of confidentiality and the dilemma of disclosure;
- the employer;
- the ill employee;
- the employee who is a carer; and
- colleagues in the workplace.

Although there is a lack of Australian legislation in place to deal with issues associated with an ageing workforce, who are more likely to be balancing issues of grief, the business sector has realised that the distinctions between work and personal life are no longer as clear and cannot necessarily be easily separated (Tehan, 2006). Given this, both grieving people and those who are carers have needs that may require support in the workplace at different points along an illness and bereavement trajectory (Department of Human Services, Victoria, 2004; National Institute of Clinical Excellence, 2004). Aspects of these supports are now discussed.

**Grief, loss and bereavement: an OH&S issue**

Grief is a workplace taboo (Aoun, 2004). If the stigma of a terminally ill employee (or an employed carer) is combined with the taboo of a grieving employee/s, the situation can be fraught with misunderstanding and
emotional struggles. Ellis (2004) suggests that grief, loss and bereavement are actually being faced frequently at work and are generally addressed as occupational health and safety issues.

Bereavement shatters our “structure of meaning” and “breaks the thread of continuity that makes the world intelligible” (Renzenbrink, 2002). It is in this context that grief manifests itself as an “ache” that accompanies the grieving person wherever they are, including at work.

Grief and loss may impair an employee’s judgment, in reduced concentration and inability to undertake tasks competently. Side effects of medical treatments, ongoing carer responsibilities, and work colleagues undertaking extra tasks to support each other, may also result in employees feeling tired, distracted and moody with a potential negative impact on workplace relationships and performance (Pawlecki, 2010). People can often be in a “time warp” where they are out of step with what is occurring around them. They come to work and fulfil their duties, attend meetings and the like, but their attention is elsewhere (Hazen, 2008).

In taking a structured view of bereavement, Australian workplace legislation (Fair Work Act, 2009) allows up to two days compassionate leave. Research clearly identifies that this approach to bereavement support is profoundly inadequate (Renzenbrink, 2002; James and Friedman, 2003). Different cultures and faith traditions require greater flexibility, as rituals and ceremonies are honoured at different times at least throughout the first year of bereavement.

The economic impact of inadequate workplace support

Two of the key issues associated with grief in the workplace that impact on employers are loss of productivity, and loss of profitability (American Hospice Foundation, 2000; James and Friedman, 2003). Workplaces providing comprehensive programs that address issues of grief and loss encounter fewer mistakes, reduced sick leave, lower staff turnover and improved teamwork resulting in sustained productivity (American Hospice Foundation, 2000).

In the USA the hidden costs of grief at work are significant (James and Friedman, 2003), but may be avoidable through improved awareness and simple, practical shifts in the way people communicate. Although grief is “emotional not intellectual”, workplaces still attempt to shift people from their emotional truths, to intellectual positions that may diminish or alter the normal reaction to the loss (James and Friedman, 2003). Workplaces may need to constantly negotiate changes to tasks and relationships to ensure that work continues through normal business productivity cycles. Such changes could include hours of work, work roles, types of work undertaken, and levels of workplace responsibility for the employer, colleagues and the ill employee or employed carer (Grierson et al., 2002; Cancerbackup, 2005; Last Acts Workplace Committee, 1999).

Some literature describes the difficulties faced by cancer survivors returning to normal life, including returning to their workplaces. Return to work rates vary and are affected by factors such as whether the work environment is perceived as being supportive (Spelten et al., 2002).

While age is not a significant factor in the decision to return to work, visible cancers (e.g. head and neck) can make it hard to return. People diagnosed with cancer while in employment tend to remain employed, even if they need time away for treatment. The reasons for this are largely practical, for example employment providing access to health insurance in the USA, but can also be less easy to define for example employment enabling a sense of control in life. Most employers are accommodating, particularly if the illness involves disability; but the employment of cancer survivors once treatment has ceased, is variable (Bradley and Bednarek, 2002).

Stigma and discrimination attached to illness

People who are grappling with grief or illness may be stigmatised in the workplace. This can happen wherever there is a perception of “otherness and difference” and may emerge at any stage in illness or bereavement (Link and Phelan, 2001). Platt and Gifford (2003), identified that such potentially discriminatory behaviour is usually brought about by ignorance. To deal with this type of social stigma, employers need to assist people to understand the difference between “illness” and “the kind of person who is thought to have or get this illness” (Platt and Gifford, 2003) through implementing a process that includes counselling and provides support services. Individual decisions around the effects of illness and disability may influence a decision to voluntarily separate (Magee, 2004). Keeping colleagues informed as the situation changes may therefore be a very important consideration in the interest of retaining employees.

The importance of this social support and social networking in the context of health should not be underestimated (Janes et al., 1986) and “those who have the greatest need of social support are, frequently, the least likely to get it” (Avery, 2002). Going to work can also be a welcome distraction from the dominance of grief the person may have at home (Charles-Edwards, 2009).
The creation of a culture of acceptance of “otherness and difference” may therefore need to be encouraged and protected through policy (International Labour Office, 2001; Connecticut Department of Administrative Services, 2005; Canadian AIDS Society, 1986; Social Partners of Barbados, 2002) or legislative means such as the Canadian Employment Insurance Act 1996, 1996. This will assist employers in supporting their employees.

**Boundaries of confidentiality and the dilemma of disclosure**

Employers need to be aware of the health status of an ill employee and/or employed carer in order to decide on, and implement, appropriate workplace support policies and strategies (Charles-Edwards, 2000). Effective workplace supports may also depend on employees’ willingness to disclose a diagnosis or their status as a carer.

The ability to discern and negotiate appropriate levels of disclosure and/or confidentiality is an important management skill when dealing with employees and workplace support issues and needs. Agreement between the employer and the individual needs to be negotiated around: “what to say, to whom, and under what circumstances” (Charles-Edwards, 2000). Boundaries around confidentiality need to be clear, because there is no justification for forcing disclosure by workers or co-workers (International Labour Office, 2001). Colleagues who understand the reasons they are being asked to support another employee through changing roles, are more likely to remain generous when the burden of work and support becomes difficult (Charles-Edwards, 2000).

Unwanted disclosure of illness can impact on emotional safety at work, job security and the maintenance of workplace co-operation and productivity. Gossip and explaining absences from work were the two most common difficulties for HIV-positive people wishing to maintain confidentiality at work (Grierson et al., 2002). Employees with HIV suggested that “employers were less concerned with legal issues and preferred to have trustworthy people as employees” regarding disclosure as a type of “risk management” (Platt and Gifford, 2003).

**The employer**

Executives may be affected by a death of a loved one (James and Friedman, 2003, p. 23), with acknowledgement that “they had made decisions when they were affected by the death of a loved one, that they would never have made under different circumstances”.

The employer plays a pivotal role in establishing a workplace culture that provides appropriate support to grieving or ill employees and/or employed carers. An effective employer understands the role the workplace can offer in supporting an employee through the grieving process (Charles-Edwards, 2000). A supportive workplace can provide a context for mourning, an escape from grieving, and be a bridge between grief and returning to “normality” (Charles-Edwards, 2005).

The USA Last Acts Workplace Committee (1999, p. 15) states that, to provide effective workplace support, managers need to know:

- what benefits and resources are available to employees;
- how to access these resources;
- how to respond to employees who ask for help;
- how to facilitate leave time;
- how to facilitate a special work schedule; and
- how to facilitate a temporary re-distribution of responsibilities.

Companies want managers to handle situations with sensitivity, consistency and confidentiality (Last Acts Workplace Committee, 2005). To achieve this, managers may themselves require support to articulate their own needs or to manage their own discomfort about staff issues like grief. Regular review or discussions about working adjustments may be required (Cancerbacup, 2005); meaning that both the employer and employee would meet regularly. Employers may need to explore creative options to help manage an ill employee’s physical and emotional limitations (Kellehear, 1999). For example, an employer could continue to value an ill employee’s contribution by re-negotiating their employment contract, or creating flexible policies for time off (Hazan, 2008).

**The ill employee**

Ill employees face a number of barriers to obtaining and retaining employment including the intermittent effects of illness, need for flexibility in taking time off, and management of illness disclosure. Additional obstacles faced by ill employees include de-skilling, shifts in life goals, ageing, and explaining an extended absence from the workforce (Grierson et al., 2002). Many ill employees feel compelled to return to work...
primarily for financial reasons, but then report difficulty in concentration and increased fatigue, usually resulting in reduced working hours (Grierson et al., 2002). Managers may need to negotiate the option of temporary or permanent discontinuation of work where an employee has a terminal illness and an employed carer may need to negotiate their return to work during the bereavement period. The need for financial security, social contact and a sense of worth are vital factors in HIV positive people’s desire to work in paid employment (Grierson et al., 2002). Similarly, it is reported that returning to work can form part of the healing process (Hazen, 2008). Survey results from Cancerbacup (2005) in the UK identifies that over half (58 per cent) of employees with cancer are keen to continue working.

The employee who is a carer
Employees who are balancing a carer role find their care giving responsibilities difficult and stressful (Briggs and Fisher, 2000). Aoun (2004, p. 10) found that “role changes within the family, lack of social support, . . . lack of control over everyday life and changes in paid employment all contribute to carer stress”. Nearly 60 per cent of carers experience negative effects on life opportunities (including paid work) and where a person takes on the role of carer (Australian Bureau of Statistics, 2009). Aoun (2004, p. 35) identified the need for “more flexible employment to reduce work conflict and give carers more options in combining paid employment and caring”.

Extending permission for a carer to take time-off – even when the person for whom they are caring is feeling well – is also an important consideration for employers (Charles-Edwards, 2000). The Princess Royal Trust for Carers, notes that “people usually take on the responsibility of caring well before they recognise that the word ‘carer’ applies to them” (The Princess Royal Trust for Carers, 2005). The burden of work and caring tasks and responsibilities may increase over time and employed carers may not be prepared for its impact or having to declare their carer status to their manager.

Colleagues in the workplace
Colleagues contribute an important role in providing workplace support for an employee living with a life-threatening illness and/or employed carer. Colleagues may try to find creative ways to care for themselves and each other within their roles and responsibilities (Charles-Edwards, 2005).

When colleagues permit the ill employee or employed carer to contribute to their workplace in meaningful and realistic ways, each person’s dignity and integrity is being valued through a spirit of mutuality (Rumbold, 2002). A pooled sick leave policy, such as that in place at the National Australia Bank Group, embodies this concept (National Australia Bank Limited, 2010). Enacting flexible leave arrangements, using discretionary funds and rearranging roles endorses a person-centred approach to workplace support.

Addressing workplace support programs
Undertaking this literature search has identified a lack of clearly defined strategies in Australia, for dealing with the sometimes complex day to day support needs of people with a life-threatening illness or carers of people with a life threatening illness whilst in the workplace.

A public health approach to healthy grief and bereavement support and death education seems an appropriate way to move forward on this issue, with general medical practices taking a key role in its provision (Kellehear, 1999). Within the context of developing a social model of practice, a health promotion approach encourages people to share experiences, information, resources, and tasks. Bottomley (2001, p. 35) suggests that effective workplace support means “creating an atmosphere of emotional safety, and . . . empathetic and active listening through clarifying, containing, being genuine, ethical, and respectful of difference”. Within this context, workplaces that practice non-judgemental listening provide opportunities to explore workplace issues and offer access to professional supervision are likely to be better able to provide support to employees with a life-threatening illness or employed carers. Tehan and Robinson (2009) describes service leadership of organisations, enacted through a vital listening to staff. Renzenbrink (2002) suggests that regular meetings between a manager and the ill or grieving employee/employed carer, to plan for the future can assist with creating a sense of safety. Similar meetings with staff and informal conversations between a manager and other individual staff members may also “hold” a workplace emotionally through periods of instability.

House (1981, p. 24) conceptualised support needs for the ill person as follows:
- economic support: helping financially, helping colleagues to do the ill person’s work;
- emotional support: empathy, caring, and trust;
- information support: to the person or to the organisation that helps them cope; and
- appraisal support: information to facilitate self-evaluation.
Employers need to be aware that tensions may emerge in the workplace as a result of the need for ill or grieving employees and/or employed carers to balance the requirements of their personal and work lives. Employers may need to introduce inclusive communication strategies within the workplace to minimise the possibility of other staff becoming resentful or not understanding the need for this balance and choosing to leave the organisation as a response.

Implications
Given that many places in the world have ageing populations, it appears extremely likely that there will be a shrinking of labour supply in the future. For example, more than one in eight Australians are involved in care giving tasks with the vast majority being of working age (Human Rights and Equal Opportunity Commission, 2007). However, it is also likely that carers are not working (even though they would like to) and are giving up full-time work or any work altogether. Despite this, there is little Australian research relating to support of an ageing workforce or a workforce that may be increasingly dealing with workers with chronic and terminal illness.

Andrews (2003) acknowledged the need for flexibility and choice around family-work arrangements in considering policy over the life course but these policies do not appear to encompass end-of-life support needs. The most recent Australian workplace legislation, Fair Work Act (2009), allows for an individual to access carer’s leave equal to ten paid days that only obliquely addresses work-family responsibilities for end-of-life care.

The Fair Work Act (2009) provision of 10 days paid personal/carer’s leave per year and two days of paid compassionate leave, perhaps implying that an employee can “get over it”, or “get back to normal” in that time. The Victorian WorkCover Authority (2005) also fails to mention life-threatening illness, loss, grief or bereavement. These approaches appear inconsistent with international findings from the literature review. In Canada, Compassionate Care Benefits allow informal carer-givers to take time off work under Canada’s Employment Insurance program. Employees can take up to six weeks leave from their work to care for a gravely ill family member (Canadian Employment Insurance Act 1996, 1996; Canadian Compassionate Care Benefit, 2004; Kirby and Lebreton, 2002). Amendments to the Canada Labour Code established that workers are entitled to a period of up to eight weeks leave with job protection to provide compassionate care to a family member (Canadian Employment Insurance Act 1996, 1996).

While workplace policies and practices vary, this review, as well as the work of the study by Bottomley (2001) highlighted several examples of workplace supports for staff grappling with terminal illness, loss and grief. The work of Tehan and Robinson (2009) also explores the value of “compassionate leadership” in assisting grieving or ill staff in their workplace. Simple examples like encouraging a workplace environment of openness, honesty and direct communication seemed to make a significant difference to how safe staff felt (Smith, 2005). This meant that employees who were carers or ill, were able to be honest about what was happening for them, as well as providing an explanation to other staff as to why the carer or ill person was absent.

The literature search located little evidence concerning actual productivity changes. Such evidence is likely to be important to employers and to strengthen the case for broader implementation of workplace supports for people with terminal illness or experiencing grief. Although the literature was qualitative and descriptive, the breadth of available literature did provide many aspects that could inform the development of workplace supports, many of them not complicated or costly. Implementing workplace supports may demonstrate a positive impact on employers through improving productivity and creating a better workplace in terms of decision-making and health and safety.

The development of human resource policies was suggested, encompassing flexible work arrangements for carers, in terms of the amount of hours worked and the possibility of working at home as well as being physically in the workplace (which also gave them time away from their caring responsibilities). Staff also valued easy access to brochures about coping with illness and loss and grief as well as the provision of workplace-based education programs.

It is hoped that the development, implementation and evaluation of workplace supports for people with terminal illness or experiencing grief will both facilitate workplace change, and also provide evidence that such change will result in benefits beyond that of the individual, and that these benefits can be measured through gains in workplace satisfaction and improved productivity.

Conclusion
Literature available on the topic of terminal illness and loss and grief in the workplace varies greatly in terms of quality and findings and the limited Australian literature is notable. Given Australia’s projected workforce demographics, policies and practices that support the reality of people’s lives in all aspects, are urgently
required. In this way, employees who find themselves wishing or needing to work while they are ill or caring for an ill family member, will not be lost to the workforce.

This literature review provides a basis for assisting workplace policymakers, employers and employees to deal with end-of-life issues and experiences. It will further assist in refining our understanding of the best “fit” that health promoting palliative support (including death education) can bring to Australian workplaces including employers/managers, colleagues, and the ill employees and/or employed carers and families served by the palliative care sector. While few studies provided empirical evidence of the benefits of implementing workplace supports for people with terminal illness or experiencing grief, we are confident that the literature does provide some evidence that the development, implementation and evaluation of a formal workplace support model will demonstrate positive measurable outcomes for the workplace.

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Further reading

About the authors
Margaret O’Connor has held the Vivian Bullwinkel Chair for seven years, which formally encompasses three clinical partners adjacent to her University campus. She is responsible for the Palliative Care Research Team in the School and manages a number of clinical research projects. Margaret sits on many state, national and international committees related to palliative care and is well published in her research areas.

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Kevin Larkins was CEO of Palliative Care Victoria from 2004 until February 2010 when he established his own business in leadership development and training, executive and business coaching. He has worked in the health and welfare industry for in excess of 25 years in Victoria Northern Territory and Western Australia in a vast array of executive leadership roles in government and not-for-profit organisations. He has worked in the acute care sector (hospital CEO), regional health (Regional Director), Community Health, Alcohol and Drugs (CEO Western Australian Alcohol and Drug Authority), Mental Health and Aboriginal Health.

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