

End-of-Life Care & Supporting Staff; a literature review

Aims of literature review:

- to provide a summary of the international literature on the need for support for staff working in end-of-life care (in palliative care and in oncology settings),
- to examine existing strategies, interventions and resources designed to provide support to staff in promoting resilience and combating burnout
- to identify any such supports which exist in the Irish context (information not yet received)

Methods: Academic Search Complete (EBSCO publishing), Pubmed, Google Scholar and CINAHL were searched using the search terms 'staff support' OR 'support for healthcare professionals' AND 'burnout' AND 'end-of-life care' OR 'palliative care' OR 'oncology.' These did not yield significant results. Individual journals and bibliographies were hand-searched to yield a total of 130 relevant articles, the most useful of which are referred to below.

Two principal themes emerged from this brief review of the literature dealing with the availability of support for health professionals working with patients at or towards the end of life. The first is the issue of burnout, compassion fatigue and loss of job satisfaction, and the second is the description of strategies or interventions designed to prevent or combat burnout, promote resilience and enhance effective care-giving. While there is a considerable body of literature dealing with burnout and compassion fatigue among health professionals in oncology and palliative care, few empirical studies have been carried out on interventions to reduce burnout and provide support for caregivers working in these areas (Le Blanc et al., 2007). Another limitation of the literature is its almost exclusive focus on the experience of nurses, particularly oncology and palliative care nurses.

(i) Stressors in oncology and palliative care

Oncology staff play a crucial role in providing physical, spiritual and emotional care to patients with serious, life-threatening illnesses (Aycock and Boyle, 2009). Oncology work is characterised by the development over time of intense professional relationships with patients and families (ref?) and by protracted exposure to suffering and death (Medland et al., 2004; Dean, 1998, Montgomery, 1998). Caring for dying patients involves high levels of emotional engagement and personal commitment (Meier and Beresford, 2006), and strong therapeutic bonds often develop between patients and staff over the course of time (Wakefield, 2000). There are many challenges associated with this kind of emotionally-taxing work. Staff are expected to provide highly effective care to patients and families in emotionally-fraught settings without receiving formal education in how to do this (Aycock and Boyle 2006). Enabling patients to maintain a sense of composure in the face of death is stressful and emotionally draining, especially for nursing staff (Wakefield, 2000). As Keidel observes, "dying with dignity' is easy to say but hard to watch, especially if the patient is emaciated, under poor pain control, has open sores or experiences haemorrhage or convulsions" (Keidel, 2002). In a study by Wenzel and colleagues, responsibility for providing treatments which increased symptoms or negatively affected patients' quality of life, even temporarily, were associated with increased caregiver stress, feelings of powerlessness, helplessness and hopelessness (Wenzel et al., 2011). Other stressors include the challenge of providing comfort care to patients with complex disease processes, being empathic towards families in the throes of psychosocial and spiritual crisis

(Abendroth and Fennelly, 2006), managing intractable symptoms (Dean, 1998), moral distress arising from conflicting beliefs about patient goals, and lack of time to grieve and reflect after a patient dies (Aycock and Boyle, 2000).

Like oncology professionals, palliative care professionals also face the challenge of working intensively with seriously-ill patients and their families at highly emotional and stressful times in their lives (Meier and Beresford 2006, Rokach 2005). Constant exposure to grief and to the experience of multiple deaths may lead to 'grief overload' (Vachon, 1998). Healthcare professionals who have developed strong interpersonal relationships with patients often share the suffering experienced by the relatives of a dying patient, and may experience a similar sense of bereavement when the patient dies (Wakefield, 2000). Staff, particularly nurses, are expected to carry on as normal after the death of a patient, and grief may become 'disenfranchised' if its expression is not sanctioned (Doka, 1989, cited in Wakefield, 2000; Montgomery, 1998; Brosche, 2007; Hill Jones 2005). Palliative care professionals rarely fully grieve their losses, and sometimes they don't have the opportunity to grieve at all. Over time, what Rokach describes as repeated 'ungrieved losses' may become "too heavy a burden to carry" (Rokach, 2005), increasing palliative caregivers' vulnerability to compassion fatigue (Abendroth and Flannery). This susceptibility to compassion fatigue and burnout among palliative care staff has not been given adequate recognition (Meier and Beresford, 2006) and the nursing profession provides no guidance on managing feelings of loss in the aftermath of a patient's death (Wakefield 2000).

Burnout and compassion fatigue

Burnout is a response to chronic work-related interpersonal and emotional stressors, and it is measured on three general scales: emotional exhaustion, depersonalisation and lack of perceived personal accomplishment (Aycock and Boyle, 2006). Professionals working in oncology and palliative care settings who experience feel isolated, overloaded, unappreciated and who do not acknowledge the effect their work has on their emotions are at risk for both burnout and compassion fatigue (Aycock and Boyle, 2009). Compassion fatigue involves an excess of empathy and undue identification with patients' suffering, resulting in an inability to maintain a healthy balance between objectivity and empathy (Aycock and Boyle, 2009). Due to the length and intensity of their interactions, end-of-life caregivers can be at risk of becoming overly involved with patients and their families; this 'unhealthy' empathy leads to the blurring of professional boundaries and constitutes a major stressor in hospice nursing (Abendroth and Flannery, 2006). This excess of empathy depletes the caregiver's own emotional resources and leads ultimately to a disengagement from patients and a withdrawal from patient care (Aycock and Boyle, 2009). Measureable symptoms of compassion fatigue include headaches, sleep disruption, increased blood pressure, cardiovascular disease, diabetes and immune dysfunction, as well as fatigue, irritability, anger and depression (Aycock and Boyle, 2009). Exhaustion, physical illness, lack of initiative and inability to cope with work stressors may result if these symptoms of compassion fatigue are not identified and managed (Aycock and Boyle, 2009). Nurses providing care to actively dying patients or to patients who suffer may also experience trust issues, loss of independence and decreased capacity for intimacy, in addition to anger, anxiety and irritability (Wenzel et al., 2011).

The suggestion is common in the literature that, due to the emotional demands of their work, health professionals working in oncology and palliative care settings are at high risk of developing burnout and compassion fatigue, resulting in poor health, diminished quality of patient care and eventual

withdrawal from the field (Keidel, 2002). Yet, despite the challenges of the profession, recent research shows that burnout and work-related stress in palliative care are not universal, and that staff working in palliative care may in fact experience lower levels of burnout than colleagues in other disciplines (van Staa et al., 2000). Desbiens and Fillion argue that the presence of emotional stressors alone is an insufficient determinant of burnout in members of these groups (Desbiens and Fillion, 2007), and that organisational and environmental factors such as heavy workload (Cohen et al., 2001), conflicts in professional relationships and suboptimal teamwork constitute significant barriers to providing compassionate care. Relationships with other health professionals may be a significant source of stress for palliative caregivers, especially when role definitions are unclear (van Staa et al., 2000). Higher burnout scores are also associated with a lack of psychological support in the workplace (Wenzel et al., 2011; Montgomery, 1998).

Identification and communication are essential in intervening to prevent caregiver stress and burnout (Keidel 2002). Both compassion fatigue and burnout are difficult to identify, and every person working in oncology and palliative care settings should be aware of the effect their work has on them and of the visible and non-visible signs of burnout (Keidel 2002). Strategies to counter burnout and compassion fatigue are described below.

(ii) Strategies for promoting resilience and preventing burnout

The literature supports the effectiveness of the following five elements in promoting resilience and preventing burnout among health professionals working with patients at the end of life: (i) the practice of self-care strategies, (ii) the creation of support groups, (iii) the cultivation of supportive interprofessional relationships, (iv) education and skill-building, and (v) meaning-making through ritual or commemoration.

1. The four dimensions of self-care

One of the biggest challenges for health professionals working in oncology and palliative care is to achieve a balance between compassionate care and self-care. Caregivers cannot meet patients' needs if their own needs are not met (Cohen et al., 2011; Huggard, 2011) and compassion fatigue is exacerbated when staff do not attend to self-care (Abendroth and Fennelly, 2006). Yet a recent study of caregiver stress ranked caring for oneself as one of the most stressful elements of providing care to terminally-ill patients (along with managing difficult interactions). Merluzzi et al. found that proficiency in self-care was associated with lower levels of stress and caregiver burden (Merluzzi et al., 2011). The interplay between personal and interpersonal resources for coping with stress is complex, but the responsibility for self-care rests squarely with the individual practitioner. Cohen and colleagues emphasise the obligation to take time for self-care; often, one is not 'given' this time; one has to take it (Cohen et al., 2001). Self-care practices include maintaining one's health and well-being, exploring one's beliefs and feelings about death and grief, knowing when to seek support and engaging in some activity apart from the caregiving situation. Another important aspect of self-care is the ability to identify and manage the limits of control in the caregiving situation.

Hill Jones (2005) describes a self-care plan for hospice professionals, modelled on the plan of care devised for patients. The plan is based on feedback from caregivers and identifies four aspects of self-care: physical, emotional/ cognitive, relational and spiritual (Hill Jones, 2005). Caring for oneself

physically involves getting enough rest, eating healthily and exercising regularly. Emotional self-care involves permitting oneself to express emotions and to grieve when needed, taking the opportunity to reflect or meditate regularly and making time for recreation and amusement. The cognitive dimension of this requires monitoring one's internal dialogue and identifying perfectionist tendencies, avoidance strategies and harsh self-judgements. Developing specific ways of letting go of the day's concerns, by practicing particular 'release rituals', can also help to prevent tensions from building up. Relational self-care involves establishing and maintaining healthy professional boundaries, developing supportive personal relationships and learning how to effectively manage interprofessional conflict. Finally, spiritual self-care requires focusing on the 'bigger picture' and finding a way of making meaning of the world and one's place in it. The use of humour is also an important aspect of relieving tension and mitigating grief (Ablett and Jones, 2007; Cohen et al., 2001).

2. Interprofessional or specialty-based support groups

In order to continue to care for patients without becoming overburdened by loss, staff require support from peers and from their organisation (Dean, 1998). Addressing the support needs of professionals working in end-of-life care may improve job satisfaction and prevent compassion fatigue (Wenzel et al., 2011; Huggard, 2011; Le Blanc et al., 2007), although there is no consensus on this issue (Barnard et al., 2006). Support provided to health professionals may be formal or informal in nature. For nursing staff, (informal) peer support is most likely to be the most common form of support (Aycock and Boyle, 2006). Informal support may also take the form of positive feedback or recognition received from management or supervisor (Dean, 1998). While in some cases this may be sufficient to improve nurse retention, more formal support structures may have greater impact on nurse morale and satisfaction. More formal supports may include debriefing sessions following a distressing or unexpected patient death or in-services explaining why patients and family direct feelings of anger and frustration at caregivers (Dean, 1998). For oncology care providers coping with work-related stressors, the most common form of assistance are staff support groups, regular meetings during which caregivers have the opportunity to discuss personal, work-related experiences and feelings with colleagues in a supportive, non-judgemental environment (Le Blanc et al., 2007).

Examples of staff support initiatives:

(i) Bereavement debriefing

In 2002, a multidisciplinary bereavement debriefing programme was developed by staff at Harriet Lane Compassionate Care, the pediatric palliative care programme at the Johns Hopkins Childrens' Centre. Over the course of a three-year period, 113 bereavement debriefing sessions took place. The purpose of the sessions was to provide emotional support to staff in the wake of a distressing or unexpected death, by offering them the opportunity to respond to the patient's death and to contextualise it in the context of their relationship with the patient. During each session, the factual circumstances of the patient's death were reviewed and the staff members who knew the patient were offered an opportunity to describe their emotional response to the situation, their coping strategies and what they learnt from caring for the deceased patient. The debriefing sessions constituted one intervention in a multifaceted staff support strategy; other interventions included palliative care education forums, patient care conferences and commemorative rituals. Staff

members who participated actively in the debriefing sessions reported an increased ability to manage grief and maintain their professional integrity (Keene et al., 2010).

(ii) Grief team

Brosche (2007) describes the development of a 'grief team' in a US critical care setting, overseen by a grief team committee, coordinated by members of the hospital's Employee Assistance Programme, but staffed primarily by experienced nurses and chaplains with training in crisis management and bereavement counselling. The purpose of establishing the team was to prevent disenfranchised grief, minimise compassion fatigue and promote the well-being of members of the healthcare team. After every death in the hospital the grief team was notified and an offer of support was made to caregivers of the deceased patient (Brosche, 2007). The outcomes of this (possibly hypothetical) intervention were not described.

(iii) Palliative care team support

In 1996, the newly-opened Palliative Care Unit in the Daniel den Hoed Clinic, now part of the Academic Hospital Rotterdam, established a support programme for the 24 members of the multidisciplinary palliative care team (van Staa et al., 2000). Before patient care activities commenced on the unit, a three-day residential training programme was organised for the team members. Conflicting expectations and insufficient clarity about the objectives of the programme muddled the team members' evaluation. Many participants had expected the programme to provide training in communication and management skills and to learning about death and bereavement. Others had expected contribute it to contribute to the creation of a common palliative care philosophy and to increase self-knowledge. The programme yielded no consensus about the content of further training sessions. Subsequent to the three-day programme, regular opportunities for staff support were provided by weekly 90-minute meetings held throughout the year and moderated by an external facilitator. Participation was non-mandatory and scheduling problems meant that there was little continuity from week to week. Initially, attendance among consultants was low, although this improved towards the end of the year. There was also some divergence of opinion about the objectives of the meetings; the facilitators and some staff members saw them as a 'safe place' where the team members could meet to discuss their personal experiences of their work or as providing an atmosphere of openness in which team members could avail of mutual support. Most members of the team, however, viewed the meetings as opportunities to raise, discuss and, in some cases, resolve specific problems. Van Staa and colleagues hypothesise that this divergence of expectations may have arisen because the support group was set up without first determining the needs and expectations of the staff involved (Van Staa et al., 2000). Despite the regularity of the meetings, the stress levels of team members rose significantly during the course of the year, but much of this was attributed to organisational factors, such as heavy workload, interprofessional discord, lack of nursing supervision and a lack of clearly defined roles for team members, rather than to the inherent nature of palliative care provision (Van Staa et al., 2000). Initial evaluations of the meeting were not very positive, but by the final evaluation the meetings were viewed much more positively. This bears out the insight that it takes time for group members to become accustomed to one another and for expectations to become aligned (Feld and Heyse-Moore, 2006). Van Staa et al. concluded that support meetings are a

valuable way of meeting the needs of palliative care staff, but that they must be adequately resourced, fully supported by management and accompanied by adequate training and attention to individual needs.

(iv) Support for doctors in palliative care

Current research on support for staff in oncology and palliative medicine focuses predominantly on the nursing profession, with little research carried out to date on the experiences of doctors or other professionals working in end-of-life care. Although doctors working in the field of palliative medicine often invest a great deal in their patients and their work (Swetz et al., 2009), few support groups exist for junior doctors working in palliative medicine. One such initiative, piloted in 2006 in a London hospice, was reviewed very positively by participants (Feld and Heyse-Moore, 2006). Despite an initial reluctance to express feelings in front of their peers, participants found the group helpful in dealing with their response to patient deaths, coming to terms with the shift from curative to palliative medicine, establishing their place in the multidisciplinary team and communicating with patients and families who demonstrated 'extreme' behaviours such as anger or withdrawal (Feld and Heyse-Moore, 2006). The group was moderated by a trained facilitator, but discussions were led by participants, all of whom found the intervention helpful and felt that it should be replicated across a range of hospital specialties (Feld and Heyse-Moore, 2006).

(v) Emotional Safety Policy

Huggard (2011) describes the development of a unique emotional safety policy by the management of the Mercy Hospice Auckland, New Zealand. The aim of the policy was to ensure that staff members felt "supported emotionally and psychologically to deal with the unique demands of palliative care work (Huggard, 2011). An Emotional Safety Committee was first set up to identify the support needs of staff and the policy was formulated on the basis of this audit. The policy specifies a range of organisational strategies to minimise staff stress and fatigue, including:

- Appropriate recruitment
- Accurate job descriptions
- Provision of a comprehensive induction programme
- Regular, structured opportunities for professional supervision and support
- Debriefing when requested or required
- Provision of regular and appropriate feedback to staff
- Encouragement of reflection and ritual throughout the work day
- Organisation of regular fora for communication (e.g., weekly team meetings)
- Timely critical incident debriefing
- Non-critical acknowledgement of personal pressures on staff
- Acknowledgement of the sadness and the burden of work and celebration of successes
- Healthy rostering

While some of these practices were already established in the hospice, documenting them in a policy underscored their importance and presented them in a manner that was accessible to staff and appreciated by them. In addition to institutional responsibilities, the policy also specified the responsibilities of individual healthcare providers:

- To avail of the professional supervision process and engage in reflective practice
- To keep a healthy work-life balance
- To use rituals to acknowledge one's own losses and to attend to 'grief work'
- To admitting and acknowledge helplessness and painful experiences
- Not to expect too much of oneself
- To maintain careful boundaries
- To engage in restorative activities
- To nurture, care for and value oneself

In 2010, staff of the Mercy Hospice participated in a national online workplace survey and was benchmarked against a number of best-practice organisations (rather than simply against other hospices and health facilities). Survey results indicated a very high level of staff engagement in the workplace: 85% of staff members completed the survey, and, of these, 95% of participants believed in the organisation, 93% felt that the organisation cared about the well-being of its staff and 93% reported that they were treated with respect (Huggard, 2011).

3. Building supportive teams

The complex demands of palliative care provision and oncology cannot be adequately met through the isolated striving of individual health care workers: the heart of end-of-life care is teamwork (Jackson, cited in Rokach, 2005). However, a team is not simply an aggregate of individuals, but "a dynamic and cohesive entity supportive of its members" (Rokach?). In the hospice setting, because the multidisciplinary team often includes individuals with different levels of professional training, ongoing team building is imperative and regular team meetings to discuss patient care challenges and other ongoing issues should be held (Dean, 1998). In their study of the 'Take Care!' programme in the Netherlands, Le Blanc and colleagues found that a targeted, team-based approach to burnout intervention had a 'stabilising effect' on chronic work-related stress, and reduced levels of exhaustion and depersonalisation (Le Blanc et al., 2007). Medland et al. examine the development of an initiative aimed at promoting psychosocial wellness and coping strategies among members of the oncology patient care team at Northwestern Memorial Hospital in Chicago. The Circle of Care retreat was a one-day workshop consisting of presentations on topics such as staying well, managing losses, developing stress management techniques, facilitating bereavement, cultivating team effectiveness and group support. A profound insight which emerged from the workshop was the recognition that providing the opportunity for caregivers to come to terms with a patient's death is a shared responsibility (Medland et al., 2004). While the retreat had a positive impact on staff, evaluation of its effectiveness is ongoing (Wenzel et al., 2011).

The work environment, interprofessional conflict and the quality of teamwork were frequently cited both as stressors and as supports by professionals in oncology and palliative care. However, issues of interprofessional collaboration, recognition and communication are outside the scope of this review for the time being.

4. Education and skill-building

There is widespread agreement in the literature that there is a need for continuing education focused on developing strategies to enhance professionals' coping skills, particularly in the absence of formalised training in specialties such as oncology (Aycock and Boyle, 2006). Sexton and colleagues argue that having a 'tool kit of coping strategies' in place is essential to prevent and

depression among critical and palliative care staff (Sexton et al., 2008). Medland et al. point out that when educational programmes for health professionals working in end-of-life care are being designed, competencies which allow them to creatively manage the emotional dimension of their role and to develop 'life and practice-enhancing skills' should be included alongside technical instruction (Medland et al., 2004). For example, novice nurses are highly vulnerable to stressors and require clinical and psychological mentorship to allow them to develop personal coping styles and to cultivate collaborative relationships at work (Medland et al., 2004; compare Wenzel et al., 2011). Le Blanc and colleagues argue that end-of-life care providers "need to be taught a rational concern, which allows the expression of feelings without impairing the ability to make decisions, rather than a detached concern" (Le Blanc et al., 2007).

[**Note.** There is a dearth of detail on existing programmes in the literature, which raises more questions than it resolves. How can 'rational concern' be taught? Need for more detailed specification of the skills required (Technical? Cognitive? Emotional? Managerial?)

5. The importance of making meaning

Health professionals may cope more effectively with repeated exposure to trauma and death-related situations when they find ways to understand and consolidate their experiences into broader meaning structures (Holland and Niemeyer, 2005). Much of the literature dealing with emotional dimensions of palliative care provision has been framed in terms of negative indicators such as distress or burnout, whereas positive indicators such as adaptability and spiritual or existential quality of life have been largely ignored (Desbiens and Fillion, 2007). Desbiens and Fillion argue that the individual ability to make or find meaning can transform intensely stressful situations into positive experiences and can serve as a 'profound motivational force' which improves quality of life (Desbiens and Fillion, 2007). In a study of the coping strategies of 117 palliative care nurses in Quebec, Desbiens and Fillion found that nurses who employed 'disengagement' strategies to cope with multiple patient deaths reported higher emotional distress, while nurses who relied on 'meaning-making' strategies displayed more vigour and reported a higher spiritual quality of life (Desbiens and Fillion, 2007). Le Blanc and colleagues argue that a focus on the rewards of caring for patients at the end of life is "essential for maintaining emotional vitality in high-risk burnout situations" (Le Blanc et al., 2007; compare Cohen et al., 2001). Cohen et al. maintain that spending even five minutes of 'therapeutic time' with patients can be healing for both patient and caregiver; therapeutic time involves time spent with patients or their families which meets their needs rather than the caregiver's agenda, listening, talking to the patient or simply being with him or her (Cohen et al., 2001).

In a related discussion, Holland and Niemeyer compared the impact of both bereavement-specific education programmes and 'everyday' experiences of spirituality on professional well-being, specifically on burnout levels. The study found that, whereas existing staff education programmes had no significant effect on burnout levels, regular spiritual experiences at the everyday level (e.g., having a sense of purpose, feeling connected, feeling thankful for one's blessings, having a belief in a 'higher power') were negatively associated with workplace burnout (Holland and Niemeyer, 2005; compare Ablett and Jones, 2006). Holland and Neimeyer concluded that, while the spiritual beliefs and practices of health professionals may vary considerably, creating a work environment which encourages expressions of spirituality (such as memorial services and other rituals) may increase staff resilience (Holland and Neiermeyer, 2005). Rituals are cultural devices which provide ways to

comprehend the often contradictory aspects of human life within given social contexts (Romanoff and Terenzio, 1998). Bereavement rituals have a purpose in that they mark the transition from life to death, assist the bereaved in creating meaning out of the person's death, and provide a vehicle for the expression of strong emotion (Romanoff and Terenzio, 1998). Holland and Neimeyer recommended that in-services should be tailored to meet the emotional needs of health professionals and should provide staff with information and training about how to start staff support groups, respond to bereaved co-workers and normalise the grief experienced after the death of a patient (Holland and Niemeyer, 2005). More generally, Wakefield (2000) recommends that the nursing profession must re-examine how it can facilitate effective grieving among nurses, allowing them to express their feelings, reflect on their grief, tell stories and say goodbye.

Unique to caring for patients who are seriously ill or dying is the need to be 'familiar with grief' and the ability to grieve as needed (Hill Jones, 2005). Professionals working in these settings, particularly in the critical care environment, need to be able to examine how they express feelings of grief and to identify what helps them through the experience (Hill Jones, 2005). Depending on personality type, some caregivers may relieve grief-related stress by talking feelings through with colleagues, while others may need to deal with it alone. Alternative ways of expressing grief may include writing and other creative activities (see Appendix). Papadatou (2009) describes grieving in this context as an active process "full of choices", in which the bereaved person oscillates between focusing on the loss and repressing it. This fluctuation is part of a healthy grieving pattern and allows the bereaved person to come to terms with their loss and to attribute meaning to it. When there is no fluctuation between experiencing and repressing loss and grief, grief overload and complicated grief can occur, leading to an inability to integrate loss and death into one's professional and personal life (Papadatou, 2009). Papadatou argues that it is vital, not only to understand how one grieves, but also to acknowledge the opportunities for growth associated with the experience of grief. She maintains that, over time, health professionals working in end-of-life care may develop a more or less coherent system of beliefs about death and dying and that this may enable them to understand better their own role and appreciate the value of their contribution (Papadatou, 2009; compare Vachon, 1998). Research is needed to determine whether staff education programmes or support groups could facilitate this awareness.

Conclusion

The literature surveyed is unanimous in its recommendation for further research into interventions to prevent burnout and promote resilience and into the efficacy of existing interventions. However, there are many variables to be considered when planning the development of interventions to provide support to staff caring for patients at the end of life. These include the needs, capacities and coping styles of individual staff members, levels of experience and training among staff members, the nature of the specialty, the culture of the ward or unit, the functioning of the healthcare team, the size of the organisation, the availability of existing resources, the amount of funding available, and the degree of institutional support for the initiative. It is a given that, if the support offered does not fit the needs of caregivers, the intervention will not be useful to staff members (Van Staa et al., 2000). The literature supports a number of different kinds of interventions, although evidence for the long-term effectiveness of many of these initiatives is lacking. Interventions should be institution- or unit-specific and their development should be based on the results of focus group discussions and needs assessments involving health professionals working in the relevant specialties.

It is likely that, in the Irish context, where many health professionals have no access to, or experience of, the kinds of interventions described in the international literature, caregivers may have a vague sense of being undersupported but yet may not be able to name the kinds of support they need.

In order to develop the concept of staff support resources in the Irish health system, the following steps are recommended as a possible way forward:

- further research into the needs of Irish healthcare staff
- key learning points from the programmes which are already in existence in individual sites need to be identified and amalgamated into a resource which could be adapted to the acute hospital setting (this could involve some kind of template or menu which would meet immediate need at a basic level).
- inviting those currently responsible for existing programmes to collaborate with the IHF on a staff support project

Appendix: supporting information

Example of a focus group study:

Focus group questionnaire (Wenzel et al., 2011), involving 34 nurses from inpatient, outpatient and pediatric oncology units in a US mid-Atlantic teaching hospital.

1. Describe a situation involving a patient in which you experienced grief or a sense of loss.
2. What did you find helpful in dealing with this issue?
3. What did you find less helpful in managing this issue?
4. Describe the essential components of a programme which would help nurses/ staff to cope with a situation of this kind.

Responses:

Kinds of loss experienced:

- Rapid deterioration of a patient's health (helplessness; frustration – exacerbated by
- Sudden death of a patient – especially where a close attachment had developed over time
- Diagnosis of recurrence (loss of hope; discouragement – affected nurses' ability to remain positive in subsequent relationships with patients)
- Prolonged attempts to sustain the lives of acutely ill patients near death, e.g., continued administration of chemotherapy (draining for nurses; created conflicting feelings about care; dissatisfaction with care delivered to patients at end of life.)

Job-related factors which exacerbated bereavement and loss:

- Nurses working at the university hospital were often so busy that they had no time to take breaks: high workload with little time for reflection or rest
- Limited time to come to terms with and manage feelings of loss (limited by the pressing needs of other patients)
- System-level improvement in communication needed to increase work satisfaction and decrease frustration. Difficulties in communicating with other personnel outside nursing (medical professionals and ancillary staff)
- Outsider misperceptions about the nature of oncology nursing

Ways of working through bereavement:

- Individual resources for coping: relaxation (massage, quiet time); religion, sport
- Team strength obtained from debriefing and dialogue: support from social workers internal to the team
- Preceptors or mentors assigned to individual nurses for guidance and support (other members of the team)
- Debriefing sessions on the unit with a psychiatric liaison nurse or members of the pastoral care team (as requested)
- Weekly psychosocial rounds following bereavement – opportunity to discuss other issues
- Support obtained through relationships with patients and their families (some families maintained contact even after the patient had died)

Suggestions for organisational support:

- Creation of mediation room or 'quiet space' on the unit
- Opportunity to take breaks

- Educational support and conference sponsorship

Barnard et al.'s survey of stressors in oncology nursing (2006): Survey of 101 oncology nurses in Australia.

Top ten stressors in oncology nursing:

1. Making mistakes
2. Feeling that there isn't time to get all one's work done
3. Witnessing care which 'goes beyond aggressive care': refusal to let a patient die
4. Watching a patient suffer and not being able to do anything about it
5. Limitations on hospital services
6. Watching a patient suffer
7. Having to continue tests on a patient who should only be receiving comfort care
8. The death of a 'favourite' patient
9. Lack of availability of equipment and supplies
10. Inadequate staffing plans

Ayock and Boyle (2009)

Three main categories of available interventions to counter compassion fatigue:

1. On-site professional resources

- Employee Assistance Programmes (wellness programmes; health screening; adequate staffing; supervision/ mentor/ preceptor arrangements)
- Availability of pastoral care support
- Counselling sessions (three free sessions provided annually – often involving extensive time lag)
- Support from psychiatric nurse/ case manager/ social worker with M.Sc.
- Support group (rarely maintained over time; poor overall attendance and unease related to group participation)
- Monthly rounds (based on Schwarz Center Rounds)
- Hosting of patient celebrations or memorial services

2. Educational Programmes

- Periodic in-services (opportunity for knowledge and skill development in coping, adaption and emotional self-care)
- Optional or mandatory ELNEC course
- Continuing education: series of classes
- Topic integrated in induction/ orientation
- Online educational resources

3. Off-site specialised retreats (rarely offered – varied response: highly valued and effective for professional renewal vs. insufficient attendance to continue)

Recommendations to avoid compassion fatigue among oncology nurses:

1. To avoid compassion fatigue or burnout, nurses can benefit from integrating self-care practices into their daily lives and should be enabled to identify ways to renew their strength and well-being.
2. Education and training in communication skills, conflict resolution, ethical issues and self-care should be included in all orientation programmes for oncology nurses.
3. Proficiency in caring for dying patients should be mandatory for all oncology nurses.

4. Where desirable, dedicated time from pastoral care staff should be requested and opportunities for collaboration should be explored.
5. Provision should be made for the exploration of feelings, whether during rounds, patient care conferences or debriefing sessions.
6. Opportunities for peer support and mentoring should be explored.

Wellness strategies of palliative care physicians (Swetz et al., 2009).

1. Promote exercise, healthy diet and physical health.
2. Promote supportive professional relationships and build collegiality
 - Promote teamwork within the MDT
 - Recognise personal limitations, rely on colleagues and share workload
 - Take small breaks during the working day for reflection or debriefing
 - Rotate professional responsibilities where possible
3. Take a 'transcendental perspective' (meditate, reflect, think about meaning and the 'bigger picture', develop a spiritual perspective or take strength from one's religion)
4. Discuss feelings with colleagues or others; debrief or avail of counselling sessions

Meier and Beresford's recommendations for preventing burnout (2006):

1. **Self-awareness, self-reflection and self-monitoring.** Health professionals need to learn to pay attention to when their stress levels start to rise, to what stresses them and to what their personal triggers are. They need to understand why they have chosen the profession they're in and what nourishes or depletes them in their work.
2. **A supportive interdisciplinary team.** This provides opportunities to discuss difficult cases and ways of responding to them, and increases the sense of control over one's working environment.
3. **Formal, scheduled support mechanisms** such as support groups. These provide dedicated time to explore personal feelings arising from patient care
4. **Mentoring from a more experienced practitioner** who understands what working with dying patients involves and who can act as a sounding-board (regionally, nationally or through professional networks if unavailable locally)
5. **Team- designated rituals or regular memorial services** to acknowledge losses and commemorate patients who have died. This helps to preserve the 'humanistic focus' of the team and acknowledges the emotional impact of their work.
6. **Develop a personal support system**, including a supportive primary relationship, and maintain a sense of balance between work and other aspects of life.

Novel approaches to reducing burnout and/ or building empathy:

1. **Pediatric Narrative Oncology:**
'Narrative training' seminar for all staff at Herbert Irving Child and Adolescent Oncology Centre, Columbia University (Sands et al., 2008)
Findings:

- During the six sessions (weekly), participants were asked to write about their attachment to patients, their emotional responses to patients and families or to try to imagine clinical situations from the perspectives for patients and family members. Narratives were then read aloud during a facilitated discussion and focus groups were arranged to discuss the effectiveness of the seminar.
- Participants found that the experience of writing narratives required introspection and exposed them to new aspects of themselves, both positive and negative.
- Participants found that the responsiveness encouraged within the seminar was transferred to their professional interactions in the work setting; some participants found that the seminar gave them the otherwise unavailable opportunity to reflect on patient's needs and on the context of the care provided.
- Some participants claimed that the seminar gave them insight into the perspectives of other colleagues.
- Participants reported that they would not otherwise have had the opportunity to reflect on the experiences they had examined in the seminar.
- The timing of the seminar required careful consideration so as not to coincide with clinical duties.
- Narrative training may be a promising method for improving the quality of care provide and the lived experiences of health professionals.

2. **Expressive writing (Sexton et al).**

- Writing about stressful events or trauma alleviates the need to inhibit thoughts, emotions and behaviours, brings about cognitive resolution, frees up working memory, and allows for closer social relationships. Expressive writing is a promising, inexpensive, and potentially cost-saving approach to help nurses and other caregivers cope with stress and upheavals.

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