



THEME

Palliative care



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Suffering, loss and grief in palliative care

BACKGROUND

The stress associated with advancing and incurable illness inevitably causes distress for patients, families and caregivers. A palliative approach to care aims to improve the quality of life for patients with a life limiting illness by reducing suffering through early identification, assessment and optimal management of pain, physical, cultural, psychological, social, and spiritual needs.

OBJECTIVE

This article outlines some of the psychosocial issues in palliative care and offers communication strategies for general practitioners to use to elicit concerns. It also discusses anticipatory and complicated grief, and provides some useful resources.

DISCUSSION

There is much that can be done by GPs, in collaboration with other services, to alleviate distress and suffering in people with a life limiting illness. In order to provide support for dying patients and their families, GPs also need to care for themselves.

Psychological distress is very common in palliative care patients and their families.^{1,2} One study reported that over half of partners will experience symptoms of psychological distress and one-quarter will have severe symptoms.³ Symptoms include fear, loneliness, isolation, a sense of helplessness, lifestyle disruption, uncertainty, and the struggle with impending death. For patients and their families, the news that a cure or remission is no longer possible is devastating and can be overwhelming. There is an accumulation of losses as the person's illness progresses, including reduced physical strength and wellbeing and the implications of a life limiting illness (Table 1). Increasing physical dependency, an inability to feed, dress or bathe oneself, or to meet personal needs unaided, causes additional psychological burden. Increasing dependence on others, the curtailment of activity, the inability to work and maintain the role in the family are all painful adjustments.⁴ Spiritual or existential issues may be raised at this time, including confrontation with the meaning and purpose of life, death and suffering.

Risk factors for distress

Distress is an understandable response to the many losses that can occur along the journey of a life limiting illness and can affect both the patient and their family. While many patients and family members manage with remarkable courage and strength, there are a number of risk factors that may make some patients more vulnerable than others for distress. These include younger age, having young children, not having a partner, and social isolation. Even for those not alone, ongoing relationship difficulties, poor mental or physical health, or other life stressors, in addition to the progression into the terminal phase of illness, may precipitate distress.⁵⁻⁹ Patients without close relatives or friends may depend entirely on health care professionals for support.

Research shows that psychological distress, depression and anxiety are almost as common among caregivers as among patients themselves.¹⁰ The patient's partner or family member often provides much of the informal care in terms of emotional and practical support, and is often intimately involved in decision making. Toward the end

of life, patients and family members may have different needs and priorities.¹¹ A recent study reported that a critical unmet need of caregivers was lack of information regarding what was happening and why, and what to expect in the future, including the final stages of life.¹²

Communication (or lack thereof) within the family can also be a source of distress. Patients may feel they are being a burden. Caregivers may feel selfish about their own levels of fatigue and their need for assistance in giving practical support, and may be afraid of not knowing what to do.¹³ Even in well functioning families, it cannot be assumed that illness brings families closer together; that all families have the same decision making style; or that all families have the same information needs.¹⁴ Some families see it as their role to protect the patient from information that may be confronting, which may further impair open communication and leave both the patient and family member feeling isolated. Patients and/or family members may need assistance to start conversations such as deciding when to stop treatment, how to make plans for the future, or what to tell the children.

Anticipatory grief, grief and complicated grief

Additional sources of distress for family members are the multiple losses and relationship changes that unfold as the person's illness progresses. Commonly family members begin to anticipate life without the patient, and some will experience intense feelings of grief associated with this loss before the patient dies.

While there is individual variation in the severity, duration and the expression of grief, most show similar patterns of intense distress, anxiety, yearning, sadness and pre-occupation, with these symptoms gradually settling over time. However, for some the experience of grief is severe and the grieving process may persist for years. As Casarett et al¹⁵ note: 'Grief changes people, and failure to return to one's baseline is therefore not a sign of abnormal grief. Instead a more realistic aim is an altered life in which the person has adapted to the loss'.

General practitioners may assist the bereaved person by acknowledging their loss and normalising – but not minimising – their grief experiences. It is important to identify those people experiencing more severe or prolonged grief reactions as these people may benefit from specialist psychological support.

For 10–20% of people, the experience of grief can become complicated and significantly impact on their ability to function.¹⁶ Complicated grief is distinct from major depression, post-traumatic stress disorder and uncomplicated grief, and includes heightened symptoms of both separation distress (eg. yearning, excessive

Table 1. Losses in life limiting illness

Physical strength and wellbeing
 Independence
 Role
 Interpersonal relationships
 Sexual function
 Physical integrity
 Life expectancy
 Control
 Mental integrity
 Safety

loneliness) and traumatic distress (eg. numbness, disbelief). For some, disbelief regarding the death with resistance to acceptance persists; they remain preoccupied with intrusive thoughts related to the death and interest and engagement in life becomes limited or absent.¹⁶ Risk factors for complicated grief include: adversities in childhood,¹⁷ a dependent type of relationship with the deceased,¹⁸ and having an insecure attachment style.¹⁹

Stress in GPs

Stress is very common among general practitioners and other health professionals caring for the dying and their families. They may feel overwhelmed and powerless in the face of both the patient and their family's suffering and distress. They may also be facing the death of a patient

Table 2. Responding to patient/family distress

Useful responses

- Empathic listening
- Acknowledge distress
- Offer a chance to talk
- Identify potential sources of distress that may be dealt with (eg. worsening symptoms)
- Offer information and practical support
- Ask about coping with own and other's reactions
- Ask about relationships, social life and communication with others
- Affirm the patient's worth when you can
- Include others to offer support when appropriate (eg. pastoral care workers)
- Treat depression and anxiety
- Ask about their expectations and fears about dying, and explore areas of unfinished business
- Follow up with family members after the death
- Consider general or bereavement counselling
- Refer to specialist services or members of the palliative care team where appropriate

they have known for many years. Furthermore, caring for the dying can challenge personal beliefs and trigger thoughts of one's own mortality.

There are several measures that may assist in reducing the stress of caring for dying patients and their families.²⁰ Acknowledging the emotional impact is important and finding someone to talk and debrief with regularly is recommended. This may include maintaining contact with members of the multidisciplinary palliative care team. It is important to develop realistic expectations regarding the support you can provide to

both the dying patient and their family. Other ongoing self care measures include finding a way that works for you to separate work and home life, having regular opportunities for training and skill development, limiting workload to appropriate levels, taking regular holidays, pursuing other interests and hobbies, and maintaining physical and mental health; such as is often recommended to patients. With adequate support and self care, providing good palliative care can be hugely rewarding and fulfilling for health professionals.

Responding to distress in patients and family members

Guidelines developed by the National Health and Medical Research Council (NHMRC) provide practical examples of what to say in response to distress.²¹ Effectively, the key is communication (*Table 2*). Often underestimated is the value of acknowledging a person's distress, offering them a chance to talk, and identifying potential sources of distress that may be alleviated. It is important to address both the patient and the caregiver's individual information needs and provide advice about practical support services.

Psychosocial sources of distress are equally important. Guidelines encourage asking people how they are coping with their own and other's reactions, empathic listening and initiating discussion on areas such as relationships and social life, and encouraging open communication and expressions of feelings between family members (*Table 3*). Active enquiry about how patients and their family members are feeling and how they are coping can facilitate this. Drawing on their long term and trusted relationship with patients and families, GPs can be in a unique position to initiate such discussions. Not everyone will want to take up this offer and some may want to talk at another time. Giving people the opportunity to ask questions may highlight areas of distress or concern and may enable the opportunity to do something to alleviate the distress. On the other hand, there are often no easy, practical solutions to alleviate suffering. The health professional's role may simply be to create a safe space for the expression of suffering. The GP knowing the patient well and being able to affirm their worth may help. Pastoral care workers may be an additional source of support, where appropriate.

Recognising and treating clinical levels of depression and anxiety in patients and their family members, regardless of the cause, is essential. Clinical levels of depression occur in approximately 25% of palliative care patients.²²

Both *Therapeutic guidelines*²³ and NHMRC guidelines²⁴ recommend that clinicians ask patients and family members about their expectations and fears about dying where appropriate, and explore whether there are

Table 3. Exploring psychosocial and spiritual concerns – ways to open the discussion

General

- What is worrying you the most at the moment?
- What are the things that are most important to you right now?
- What are your biggest worries or fears?
- How is your health situation affecting you emotionally?
- Would you say that you sometimes feel very sad or depressed?
- Anxiety is common in people with an illness such as yours. Have you been feeling anxious lately?

Relationships and social life

- How is your family coping with what is happening to you?
- How has your family's reaction impacted on you?
- Do you worry about being a burden to others?
- Do you worry about how your family will cope without you?

Expectations of dying and what may happen in the future

- Some people are worried about things that may or may not happen in the future. It can help to talk about this. I am very happy to talk to you about the future. Do you have any questions or concerns about that?
- Is there anything that is worrying you about the future in terms of managing your symptoms?
- People who have an illness such as yours may experience worries or concerns about how they will manage as their disease progresses. Is this on your mind?
- It is very difficult for any of us to contemplate our own death. Are there particular fears or issues concerning you about dying?
- Have you been with anyone else going through the same thing/dying? How was it for them? Is there anything about what happened to them that worries you?
- What are your biggest concerns for the people you will leave behind?

Spiritual or existential concerns

- What are the things in life that give you strength and sustain you?
- Do you belong to any specific religion, faith or community?
- Is God, religion or any other spiritual belief significant to you?
- Are your beliefs being challenged by your current experiences?
- Do you have someone to talk to about spiritual matters?
- Is prayer, scripture, music, meditation or reading helpful?

Table 4. Useful resources and services**Palliative care**

- Palliative Care Australia www.pallcare.org.au/
- Caresearch www.caresearch.com.au/
- Australian Department of Health & Ageing (Palliative care section, click on link to information brochures for carers) www.health.gov.au/palliativecare
- State Cancer Councils – Helpline, Counselling service, local resources, support groups www.cancer.org.au
- Cancer Helpline 131 120

Bereavement services

- Australian Centre for Grief and Bereavement www.grief.org.au/
Phone 03 9545 6377 or 1800 642 066
- GriefLink www.grieflink.asn.au/frameset.html
- National Association for Loss and Grief (Australia) Inc www.griefaustralia.org/
- Solace Grief Support www.solace.org.au
Phone 08 8272 4334 Griefline 03 9596 7799
- Lifeline (National) www.lifeline.org.au
Phone 131 114

areas of unfinished business. Following up with family members after the death, by phone or letter, offers more than condolence in general practice – it can enable the opportunity to check how family members are coping with bereavement or provide clarification of medical issues. The option of general or bereavement counselling may be worth discussing with patients and family members at different times throughout the end of life period (Table 4).

Conclusion

While this article has covered many psychosocial concerns in palliative care, the words of American author Therese Rando may be reassuring. 'No one has to die in the state of psychoanalytical grace... and few if any people die with all their complexes worked through'.²⁵

However, there is much that can be done by all members of the health care team to alleviate distress and suffering. In order to be able to provide support for both the dying patient and their family, health professionals also need to look after themselves and each other.

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