

Extract

Bereavement in primary care mental health

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KEY MESSAGES

Abnormal bereavement and distress disorders are prevalent and carry a significant rate of morbidity and mortality.

Complicated grief treatment is more effective than standard interpersonal therapy in terms of response rate and time to response for complicated grief.

Healthcare professionals are in an excellent position to help the individual with distress disorders or abnormal bereavement to prevent both physical and psychological morbidity.

Counselling by minimally trained community workers in underprivileged communities has shown beneficial effects for anxiety and depression. It is recommended that skills for identification and counselling for distress disorders and abnormal bereavement should be incorporated in the training of community health workers in resource-constrained countries.

Introduction

Distress disorders are common in primary care and the previous chapter (Chapter 15) on anxiety describes the epidemiology, key symptoms and investigations necessary when dealing with distress disorders, including information-gathering decision-making, self-help and treatment options.

Many family doctors are used to seeing patients who have experienced life events that lead to psychological disturbance. One such common life experience is that of bereavement, and all family doctors and their teams will come across patients who have experienced bereavement.

While the proposed new edition of the International Classification of Diseases, ICD-11 may not include bereavement as a distinct entity, because it shares so many features with other distress disorders,¹ we will use it as an example of a life

transition that is followed by psychological disturbance.

What is bereavement?

Bereavement can be defined as the period of mourning and grief that follows the death of a loved one. Mourning consists of the rituals and symbolic behaviour that follow such a death. These features could, for example, include the funeral and the wearing of black clothing. The mourning rituals vary according to the culture and religion of the deceased and the bereaved.

Grief refers to the individual's experience of loss and comprises physical, psychological and spiritual responses.

Bereavement is an experience that virtually all individuals will experience at some point in their lives. It can be seen as a normal part of the life-cycle. Although it is a common phenomenon, it is usually not familiar as a personal experience to the person concerned and is associated with high levels of emotional distress and increased levels of morbidity and mortality.

Bowlby's work on attachment and its exploration of separation and loss has been highly influential in the understanding of grief.² His work on the development of the attachment between infants and their mothers highlighted the behaviours designed to bring about reunion after separation – crying and searching. Since such behaviours are so necessary for survival at the start of life, it is to be expected that the same behaviours, along with separation anxiety, will surface at a time of loss in later life.

There is a wide range of emotional and behavioural components within the grief response of the bereaved. The nature of the response is influenced by the individual characteristics of the bereaved, the nature of their relationship with the deceased, the circumstances of the death and the culture of the bereaved person.

Many authorities on bereavement, Parkes and Prigerson in particular,³ have described well-recognised features that are usually present in the bereaved. These accounts describe the expected components, their sequence and their approximate timescale. Such models of understanding also rehearse a cycle of response that emphasises the natural history of grief with expected phases and their eventual reduction in intensity. The majority of bereaved people come through their grief and resume their everyday functioning, albeit with an adapted psychological framework into which the death is integrated.

There is an acknowledgement that there is benefit through the grief process running its course and also that there are factors that can be associated with promoting this process. The blockage of such a process for whatever reason may leave the person stuck in responses and attitudes that are painful and not conducive to emerging from the bereavement in a healthy way. Complicated or prolonged grief is highly disabling and associated with high levels of suffering. Healthcare staff have a vital role to play in supporting the bereaved; in identifying when a prolonged, complicated or abnormal bereavement has developed; and in providing or referring the person for appropriate treatment.

In descending order, the death of a child, a spouse or partner, or parent are said to be associated with the highest intensity of adult grief.⁴ The loss of a

loved one through suicide may also be recognised as having a particularly profound psychological impact. Bereavement is known to be associated with increased levels of morbidity and mortality.² It is therefore incumbent on health staff to pay careful attention to patients suffering such loss. There is considerable scope for interventions that can make a real difference to the level of suffering and the health, functional and social outcomes of the bereaved.

Key tasks for healthcare professionals include the possession of good knowledge about the normal spectrum of bereavement reactions, skills in promoting grieving, and an ability to identify when a grief reaction has become abnormal, prolonged or complex, or when it has developed into a mental illness such as depression.

Additional skills include an ability to identify and know how to help children and those with communication difficulties to manage their grief.

An understanding of infant attachment is helpful in assisting bereaved children. Infants and toddlers react to the loss of an attachment figure by protesting vigorously, followed the experience of despair and eventually detachment. By the age of five years, most children can understand the difference between a temporary separation and a permanent one as in death.⁵

Florid reactions do not tend to last longer than a few weeks but bereaved children have higher levels of emotional disturbance and symptoms than non-bereaved children. Early bereavement is associated with higher levels of childhood psychiatric disorder, and adults who lost a parent in childhood are more prone to psychiatric illness.

Stages of the bereavement process

Numbness/disbelief

There is a sense of disbelief and a failure to behave in a way that takes account of the loss of the loved one. The expectation that the bereaved person is about to see the person, that they will shortly walk through the door, makes for a recurrent feeling of alarm and intense distress when the reality of the death is repeatedly realised.

Yearning/pining

This is a phase of intense 'pangs of grief' associated with anxiety representing separation distress. There

is a feeling of emptiness coupled with a longing for the lost person. Searching behaviours are part of this phase and can entail the literal looking for the person, perhaps where they would have spent much of their time when alive, or alternatively it can mean a process of mental searching, or searching within to try to find a sense of connection with the lost person.

The bereaved person may find themselves identifying with the deceased's illness and experiencing their symptoms. They may also develop a strong sense of the presence of the dead person, typically by seeing or hearing the deceased in varying degrees of intensity but usually fleetingly.

Anger

It is not uncommon for there to be emotional responses that may be difficult to accept or understand. Anger is a relatively common response, most easily understood in terms of the bereaved person feeling they have been left or deserted to cope with not only their grief, but also whatever unresolved life situations have been left by the deceased. More complex motivations for feelings of anger may also develop in bereavements where the relationship between the dead person and the bereaved person was difficult, unhappy or ambivalent.

Sadness/depression

This phase of grief is one in which the full enormity of the loss is realised, and can entail a loss of all interest, enjoyment and motivation, weight loss, impaired concentration and short-term memory, disorganisation and despair. Guilty feelings that the bereaved person could have in some way done something to prevent the death, alleviated the dead person's suffering or acted in any other way for a better outcome are extremely common. Again, such feelings can be more intense, persistent or difficult to deal with when the relationship with the dead person was problematic.

The most intense grief and peaks of distress usually begin to recede after four to six months.^{4,6}

Resolution/acceptance

Over time, it is usual for the bereaved person to experience a gradual lessening in the intensity of their grief. The positive aspects of the dead person's personality and life are recalled with a mixture of both sadness and pleasure, and a more rounded view of the person is developed or regained.

While the sense of loss and pain does not disappear, the strength of the distress recedes and it is possible to begin to find meaning and enjoyment in life once again.

The bereaved person is able to recognise and hold on to a balanced view of the dead person, in which the positive and less positive features of the person are recalled; the sense of long-term psychological connection with the person is maintained; there is a return of an emotional equilibrium and the bereaved person can continue with their life.

Abnormal bereavement

A small proportion of the bereaved are known to undergo a more problematic, prolonged and complicated course. A number of studies have sought to characterise and differentiate those who develop what can be described as pathological grief from those that do not. Personality vulnerabilities leading to such relationship styles as avoidant and insecure attachments are likely risk factors.⁷ A genetic marker of response to adversity may contribute.⁸ Previous loss and adverse life experiences, such as those experienced by indigenous peoples losing land, culture and loved ones are described as further vulnerability features.⁹

Separation anxiety in childhood, previous psychiatric disorder, a history of family psychiatric disorder and substance misuse are all thought to increase vulnerability.¹⁰

Diagnoses of patients studied in such research fall into two categories, specific and non-specific.³ The non-specific conditions include a range of psychiatric illness that can be triggered by a number of types of stressors as well as bereavement. The specific conditions are forms of complicated grief. In reality, bereaved people can sometimes show evidence of both non-specific disorder and specific disorder (pathological grief), i.e. a mixed picture.

Two main categories of abnormal grief have been described: prolonged grief disorder (PGD) and delayed or distorted forms of grief. PGD is now well established and the most frequent form of pathological grief, while the other category remains less well established.

There is no well-defined cut-off point between complicated and uncomplicated grief; they are thought to exist on a continuum.

Separate teams have carried out systematic studies on prolonged grief,^{11,12} and subsequently reached agreement on the cluster of phenomena that are commonly present in those with PGD.

For PGD, Prigerson and colleagues have developed consensus criteria for a psychiatric disorder for provisional inclusion in DSM-V.¹³ The proposed definition requires that the reaction to the loss includes not only the presence of prolonged grief but also a cluster of at least five of the following:

- sense of self as empty or confused since loss, or feeling that a part of oneself has died as a result of the loss
- trouble accepting the loss as real
- avoidance of reminders of the loss
- inability to trust others since the loss
- extreme bitterness or anger related to the loss
- extreme difficulty moving on with life (e.g. making new friends, pursuing interests)
- pervasive numbness or detachment since the loss
- feeling life is empty and the future bleak without the deceased
- feeling stunned, dazed or shocked by the loss.

The symptoms would need to have lasted at least six months, be associated with a significant level of functional impairment, not be due to the effects of a substance or a general medical condition and not be better accounted for by major depressive disorder, generalised anxiety disorder or post-traumatic stress disorder (PTSD).

Simple enquiry for key symptoms can likewise detect the presence of specific psychiatric illness such as depression. Grief measures can potentially offer a more structured means to clarify the presence of, and differentiate between, prolonged grief, depression, PTSD or other health problems.¹⁴ Such structured measures are unlikely to be routinely necessary in primary care.

Prigerson and colleagues have developed a questionnaire called the Index of Complicated Grief (ICG),¹⁵ since superseded by a simpler 13-item Prolonged Grief index (PG-13). In practice, the observation of intense levels of grief that last beyond six months along with symptoms from the list of criteria suggested for inclusion in DSM-V would be indicative of a diagnosis of PGD.

Management of distress disorders including bereavement

The principles of assessment and management of anxiety disorder should be followed. These are presented in detail in Chapter 15.

Special considerations for the assessment and management of bereavement

For most bereaved people, counselling and specific treatment are not required. Assessment should be simple and carried out at the time of need, looking at the death itself, the circumstances, the nature of the relationship with the deceased and the bereaved person's experience since the death.

Assessment and initial management of the bereaved should be carried out in a sensitive, empathic and compassionate manner.

Just as in the case of distress disorder, where grief is particularly intense, complicated or prolonged, or where there are vulnerability factors, careful history-taking is important. It is then important to consider eliciting information in a systematic way about the effects of the death on the bereaved person and the progress of their grief. Suggested areas for focus include the presence and extent of symptoms associated with the known phases of grief:

- numbness and disbelief
- yearning and sadness
- anger
- guilt
- suicidal thoughts
- the meaning for the individual of their loss.

Evidence of particularly intense or prolonged reactions requires more detailed consideration. Vigilance for the presence of depression, anxiety disorder or PTSD is required.

Management of distress disorder and bereavement

Management of distress disorders including abnormal bereavement may depend on culture and resources, including the use of available social network and family support and can often be delivered in the primary care setting.

There is limited evidence for the effectiveness of specific treatments. The following guidance is based on suggested approaches from the literature, the authors' views drawn from practical experience, and the available research evidence base.

The role of primary care services

- Consider the diagnosis.
- Acknowledge the condition.
- Provide education and information about distress disorder and bereavement.

- Consider the provision of therapy that is supportive, active, flexible, goal-directed, time-limited, supportive of the patient's strengths and of a type that plays down past problems.¹⁶⁻¹⁸
- Consider brief therapies with three broad components:
 - enabling reduction or removal of the stressor
 - measures to facilitate adaptation
 - altering the response to the stressor-symptom reduction/behavioural change.

Therapeutic approaches that may be helpful include problem-solving, cognitive restructuring, mobilising support such as the involvement of family members, relaxation techniques and dialectical behavioural therapy for deliberate self-harming behaviour.

Psychological therapies of a variety of modalities, including supportive, psycho-educational, cognitive and psychodynamic therapy, may all be of use. The evidence base for these approaches is limited.¹⁹

In distress disorder associated with bereavement, cognitive approaches can be useful, as described in the Dutch guidelines for the diagnosis and treatment of adjustment disorder.^{20,21}

These guidelines are seen as best implemented within a scheme in which there are three phases:

- understanding and coping emotionally with what has happened, thereby gaining understanding and acceptance
- gaining insight into the relevant stressors and possible solutions and the acquisition of skills to implement solutions
- the application of skills and solutions.

A key principle within the implementation of this approach is active monitoring of the recovery process, seeking to ensure patients fulfil planned recovery tasks.

The limitations of these recommendations include the fact that they are mainly designed for work-related adjustment disorder and the physician (occupational health physician or general practitioner) requires specific training to provide the intervention.

Interventions in prolonged grief disorder

Systematic review of the current literature on bereavement intervention has revealed no consistent pattern of treatment benefit across well-designed experimental studies;²² indeed, a universal treatment for complicated grief may not exist, as grief can be viewed as a multidimensional construct.²³

Shear *et al* conducted a randomised controlled trial that compared complicated grief treatment (CGT) with standard interpersonal psychotherapy (IPT) and found the former treatment to be more

effective in terms of response rate and time to response.²⁴ The CGT protocol included an introductory, middle and termination phase. In the introductory phase, the therapist provided information about normal and complicated grief and described adaptive coping and adjustment to the loss. In addition, it included a focus on personal life goals. In the middle phase, the therapist addressed both processes in tandem. The termination phase focused on review of progress, plans for the future and feelings about ending treatment. IPT mainly focused on behaviours and relationships, whereas CGT focused on the dual problem areas of distress caused by the loss and the survivor's personal goals and restoration of a satisfying life. Basically, it is two-pronged approach in which therapists simultaneously guide patients to focus both on the loss and on rebuilding their own lives.

CGT is a psychotherapeutic approach that includes cognitive-behavioural methods similar to those used for PTSD. In CGT, therapists guide patients as they narrate the story of the death, a process called 'revisiting', and produce audio recordings of the exercises that enable patients to listen to the story repeatedly and put aside the thoughts about the death, thereby lessening the effect of the pain. The patient is encouraged to make specific plans for pleasurable activities and to start to engage in situations that he or she has avoided following the loss of their loved one. The therapist also guides the patient through an imagined conversation regarding the person whom he or she has lost, which offers the opportunity to speak openly about the intense feelings that the two shared. At the same time, patients work on re-engaging in activities and relationships that promise satisfaction and work to define and achieve personal goals. Both patients and therapists evaluate the patient's symptoms throughout the course of the therapy.

The key findings from this study were that response rate and time to response were significantly better for CGT than IPT.²⁴ Also, those participants who were already taking an antidepressant drug at the time of their enrolment showed twice the response rate to IPT and slightly better results with CGT than those not on medications.

Recently, an internet-based cognitive-behavioural intervention for complicated grief has been developed and evaluated by Wagner and Maercker.²⁵ This is a five-week intervention that consists of two components: structured writing disclosure and cognitive-behavioural therapy. Results of this randomised controlled trial revealed that the treatment group experienced significant statistical and clinical reductions in various symptoms (e.g. intrusion, avoidance, failure to adapt) at post treatment and at three-

month follow-up. Wagner and Maercker also reported that the reduction in symptoms of complicated grief observed after treatment with an internet-based cognitive-behavioural intervention was maintained at 1.5-year follow-up.²⁵ A recent meta-analysis conducted by Wittouck *et al* concluded that treatment interventions can effectively diminish symptoms of complicated grief in both the short term and long term.²⁶

Recommendations for primary care staff when responding to bereavement

The provision of empathic, sensitive and compassionate support is a key requirement in the initial stages. Guiding principles include acting in such a way as to do no harm, to seek to protect the patient's mental health, and to anticipate and acknowledge the potential sequence of fluctuating and mixed emotional responses.

Answering questions about the deceased and their death, their illness or injuries, and their suffering can be very important.

Support to enable the bereaved person to view the body, and guidance on practical matters to do with the funeral, are often of great value.

There is limited evidence to support guidance on how primary care staff should respond to bereaved patients. There is some evidence on how primary care doctors and nurses respond in the UK.²⁷ Based on such work, it is considered desirable for general practitioners (GPs) and practice nurses to offer support to all patients who are bereaved and to seek to proactively engage those who are judged to be at risk of an adverse bereavement outcome.

The aim of such intervention would be to provide support to the bereaved in a non-intrusive, responsive and practical way, highlighting the use of the patient's own resources and without interfering in a process that could be at risk of being over-medicalised.

The role of primary care services

- Establish contact with the bereaved. This may involve developing a system to alert the primary care team to this need when there is a death. The contact can be made by doctors or nurses, in person, by letter, appointment or home visit.
- Provide information about the death.

- Give information about bereavement and offer support. Remain available.
- Offer to listen/talk: show a willingness to hear the bereaved person's account and to acknowledge their grief.
- Consider the potential role for anxiolytic or hypnotic medication in the short term.
- Provide supportive counselling.
- Identify abnormal bereavement/complicated grief. If the timescale of intense distress exceeds six months and there is ongoing significant functional impairment, this would suggest a complicated grief reaction and/or the presence of a psychiatric disorder such as depressive illness, anxiety or PTSD.
- Identify depressive illness, PTSD and any other mental illness.
- Treat depressive illness with cognitive-behavioural psychotherapy and consider antidepressant medication, particularly where symptoms are severe.
- Bereavement counselling services: most acute hospitals in the UK have bereavement services attached to them. Patients can be referred by primary care staff and can also refer themselves.
- Give information about bereavement organisations such as Cruse Bereavement Care.
- Refer on to primary care-based treatments or refer to secondary care mental health services if grief is intense, prolonged or complex.
- In the UK, consider referral to the local arrangements for improving access to psychological therapies (IAPT).
- Systematically review the progress of those who have risk factors and/or those who are known to be experiencing abnormal or prolonged reactions.

The role of mental health services

- Mental health services such as practice-based/linked psychology and counselling interventions may be available at a primary care level. Where the bereaved person is seeking further help and where distress levels are high, referral to such support is indicated.
- Secondary care mental health services: primary care staff should consider referral to specialist psychiatry services when there is evidence of complicated grief that is not responding to primary care-based psychological interventions; where depressive illness has not responded to initial treatment; where there is significant suicidal thinking; or where there is diagnostic or treatment uncertainty.

Conclusion

Distress disorders are part of the spectrum of dysphoric disorders. This chapter has specifically focused on bereavement, an example of a distress disorder that all family practitioners will encounter in their practice.

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