

Progress in understanding Grief, Complicated Grief, and caring for the bereaved

Anthony W. Love,

School of Psychological Science

La Trobe University

Bundoora Victoria 3086

Australia

a.love@latrobe.edu.au

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Abstract

Grief occurs with loss of symbolically important connections and involves intense emotional reactions and changes to our experiences of self, the world, and the future. Individual responses reflect factors such as personality and life history, social context and cultural practices, and the symbolic magnitude of the loss. Grieving can be a relatively slow and uneven process, so applying prescriptive stages or goals to individuals' experiences can be unhelpful. Although most people are resilient in the face of loss and do not require special interventions, health professionals can contribute by empathic use of communication skills to facilitate the grieving process. A minority will struggle with their grief and experience prolonged, intense, or problematic reactions. Psychiatric comorbidities including depression and anxiety disorders can occur, and a distinct diagnosis of complicated grief disorder has been proposed. Health professionals can identify complicated grief reactions and ensure patients receive specialised treatment, including intensive grief therapy and medication where indicated. Assessment methods are summarised to assist health professionals in providing a continuum of care for those who are grieving.

Keywords: assessment; bereavement; depression; grief; loss; nursing

Introduction

Humans construct their worlds symbolically, creating meaning from experience and investing relationships with rich connections and emotional bonds (Neimeyer, 2006). Disruption to or loss of significant attachments is referred to as bereavement. It almost inevitably produces intense, overwhelming reactions, known as grief (Parkes 1996).

Those experiencing grief may feel as though they will never emerge from the devastating anguish. Yet grief is a normal reaction to loss and is not usually associated with long-term negative consequences. The suffering of dazed confusion, waves of distress, and unrelenting despair will generally ease in intensity and frequency. For most, the typical course will include fluctuations between anguish and acceptance. Prescriptive timelines and set stages for resolving grief cannot be imposed (Neimeyer 2000) and indeed the notion of full recovery is itself contentious (Carnelley, Wortman, Bolger & Burke 2006).

Despite their misery, most grieving individuals will not require special intervention. The majority do not need, nor benefit from, a bereavement group or formal grief therapy (Jordan & Neimeyer 2003, Stroebe 2005). With time and the support of their social networks, most people adjust their worlds, making sense of the loss and pain, and reshape understanding of their lives. Nonetheless, typical tasks of grieving can be identified and support from resourceful, sensitive others, including well-informed health professionals, can assist this transition and facilitate a productive resolution. One purpose of this paper is to summarise current knowledge about the grieving process and outline ways of helping those who are grieving. Communication skills and strategies for facilitating uncomplicated grief reactions are described.

A minority will be at risk, following their loss, for mental and physical complications. These can take many forms, including psychiatric comorbidities, such

as major depression and anxiety disorders. Consensus is emerging that a distinct category, complicated grief disorder, can occur. A second purpose is to update knowledge of the complications that can arise. Careful assessment can aid early identification of complications and indicate when specialised intervention is warranted. Health professionals can contribute to the management of atypical grief reactions and ensure that additional professional assistance is provided where needed.

Grief Reactions

Normal or uncomplicated grief

Grief is essentially an unavoidable human experience that becomes increasingly prevalent with age, especially for women (Parkes 1997). Although it is common, grief is highly varied in both its features and its patterns (Genevro, Marshall & Miller 2004). Within this variation, there are five broad domains of grief reactions (figure 1):

<INSERT FIGURE 1 ABOUT HERE>

Emotional — grief may involve feelings of sadness, anger, guilt, anxiety, fear, shame, relief, jealousy, hopelessness and powerlessness.

Cognitive — changes to thinking may include obsessive preoccupation with former attachments, poor concentration, fantasising, apathy, disorientation and confusion, ruminating about the circumstances of the death, experiencing a sense of the presence of the deceased and trying to make sense of the loss.

Physical — somatic symptoms may include headaches, muscular aches, physical pain including abdominal or chest pain, fatigue, nausea, menstrual irregularities, noise intolerance, tension, and appetite and sleep disturbance. It can also have more subtle effects, such as reduced activity of natural killer cells in the immune system and

higher levels of the stress hormone cortisol compared with non-bereaved individuals.

People may also neglect their usual diet, exercise, and medication regimens.

Behavioural — the bereaved may report constant crying or agitation, coupled with increasing illness behaviours, such as frequent visits to their GPs. They may variously describe being social withdrawn, increasing use of alcohol, searching for the deceased, avoiding reminders, increasing physical activities, and attempting to maintain a sense of connectedness by, for instance, incessant visits to the cemetery.

Existential — disruptions such as the death of a loved one can precipitate searching for meaning in death and the questioning of spiritual beliefs and values, often resulting in a re-evaluation of core beliefs.

Because grief is a dynamic, changing process, responses will manifest in a variety of ways at different times (Maciejewski et al. 2007). Strong responses emerging after relatively settled periods may be part of normal grief reactions. By themselves, they do not indicate that the person is experiencing an atypical form of grief (Lobb et al. 2006).

Early theorists' contributions to understanding grief are familiar to many (e.g. Bowlby 1980, Kubler-Ross 1981). Kubler-Ross proposed a five-stage model of anticipatory grief experienced by people facing death. She suggested that they first experience denial, where shock and disbelief predominate. Her second stage, anger, suggests the person struggles to answer the question 'why me?' Next is bargaining, where the person makes deals with fate or a higher power in return for a cure. The fourth stage involves depression and despair, as the person recognises the inevitability of death. Finally, acceptance represents a stage of relative serenity, where the person accepts his or her fate.

While this model was important in pioneering grief research, its limitations are well known (Maciejewski et al. 2007). It was developed for people with terminal illnesses, not for the grief reactions of survivors, so does not fully capture their experiences. The process of grieving is rarely as linear as the model suggests and people do not necessarily progress by transcending supposedly lower-level reactions, such as denial. Unfortunately, this descriptive model frequently employed as a prescription for how grief should progress. Fixed, predictable stages may be used implicitly to evaluate anyone who does not follow this pathway. It has led to common aspects of grieving, such as regression or early acceptance, being misidentified as evidence of complicated grief reactions.

Yet it is instructive to consider these stages as general patterns of grief experience (Maciejewski et al. 2007). At first, people can often react to news of loss with shock and denial. They might initially report disbelief and numbness, experience pining, yearning, and a desire to be reunited with the loved one. A phase of acute anguish might then emerge that includes waves of somatic distress, withdrawal behaviour, preoccupation with the loved one and feelings of anger, guilt, and depression. They might be restless and agitated, while reporting feeling aimless and unmotivated, and the purpose of living can be questioned. A resolution phase can emerge, which reflects a sense of having grieved intensely and now feeling less overwhelmed by intense emotions. People might resume previous roles, such as work, or adopt new roles, as they begin to re-experience pleasure from ordinary activities and social relationships. It is important to stress, however, that these experiences are not prescriptive stages that people should inevitably pass through, even though they are still often understood this way (Maciejewski et al. 2007). Non-judgemental

listening, acceptance, and supportive encouragement are far more helpful. Some suggestions for facilitating grieving are outlined below.

Complications of grief

When grief does not resolve within a reasonable time, or individuals have extreme experiences, the process is probably no longer adaptive (Ray & Prigerson 2006). Estimates of the proportion experiencing complications vary between 5 and 20% (Monk, Houck & Shear 2006, Stroebe et al. 2001, Zisook 2000, Prigerson, Maciejewski & Newsom 1995). Grief can be complicated by psychiatric conditions such as depression and anxiety (Lichtenthal, Cruess & Prigerson 2004). In addition, there is a growing consensus that strong evidence exists of a distinct diagnostic category of prolonged grief reaction, which needs to be differentiated from these disorders (Bonanno et al. 2007). Various terms have been used to describe such reactions, for example, abnormal, unresolved, maladaptive and traumatic. Recently, the term complicated grief reaction has become more common and a systematic review of the field, which is beyond the scope of this paper, has been published (Kristjanson et al. 2006). Those seeking more detailed information are advised to consult it.

Proponents argue that complicated or prolonged grief requires more complex, multi-modal therapies and have prepared operational criteria for its inclusion in future psychiatric taxonomies (Ray & Prigerson 2006). Although it is contentious (Lobb et al. 2006), this perspective highlights the importance of careful assessment, which can identify the needs of and guide treatment interventions for complex problems stemming from significant loss (Monk, Houck & Shear 2006).

Risk factors for complications of grief have been identified (Aranda & Milne 2000). The main themes have been summarised in Table 1.

<INSERT TABLE 1 ABOUT HERE>

Depression and grief reactions can be distinguished with careful assessment (Ray & Prigerson 2006). While they share many common characteristics, such as feelings of sadness, insomnia, and poor appetite, strategic questioning reveals important distinctions. For example, in grief, guilt is usually restricted to events around the death of the loved one, and thoughts of death involve wanting to be reunited. Depression is associated with more global feelings of worthlessness, and thoughts of death with suicide. Depression symptoms also include psychomotor retardation, extreme weight loss, delusions, fantasy relations with the deceased, withdrawing socially, and searching for the deceased.

Because of the similarities, current psychiatric diagnostic criteria exclude the diagnosis of major depressive disorder within the first two months following loss, when the depression-like phenomena tend to be transitory and self-limited. If they persist for longer, however, a diagnosis of major depression might be warranted. Prognosis is generally good for such cases and with treatment, usually involving referral to a specialist for psychotherapy and pharmacotherapy, recovery can be anticipated (Zisook 2000).

Anxiety symptoms are very common and reactions such as generalised anxiety disorder or panic disorder also may be prominent in grief (Jacobs & Prigerson 2000). Fear can relate to concerns for the future, while reminders of the deceased may precipitate panic attacks. Social isolation and loneliness can exacerbate the pain of grief and create a type of separation anxiety. Other anxiety disorders, such as obsessive-compulsive disorder, can emerge or become exacerbated during grieving, requiring careful assessment and management (Zisook, 2000).

When the loss was sudden, unanticipated, or the result of trauma, other complications can arise. Individuals often feel overwhelmed, unable to cope, incapable of comprehending the loss, seeing the world as particularly chaotic, and they may even experience symptoms of Post-traumatic Stress Disorder (PTSD), such as numbing and intrusive thoughts, as well as hyper-arousal and avoidance (Jacobs, Mazure & Prigerson 2000). Treatment for PTSD is indicated, with some experts arguing that it should begin before grief work is commenced.

Complaints about poorer physical health often accompany grief (Parkes 1996). Widows have poorer physical health and greater unintentional weight loss over a three-year follow-up (Wilcox et al. 2003) and widows experiencing traumatic grief are at greater risk of long-term ill health such as cancer or heart attack (Chen et al. 1999). Health service use may increase significantly with complicated grief reactions (Ray & Prigerson 2006). Increased service use thus might indicate risk of grief-related complications, signalling the need to ask about recent changes in physical functioning and providing opportunity to offer support that is more appropriate.

Children and adolescents are susceptible to complicated grief reactions. They often have greater difficulty adjusting as they have fewer emotional, cognitive, and social coping resources. Loss of attachment figures is particularly devastating for them. Sibling death can also be complicated (Packman et al. 2006). They thus require careful assessment and support throughout their grieving. Referral to specialist services in these cases is often advisable.

Assessment

Assessment of grieving individuals may include standardised measures (e.g., Prigerson et al. 1995), observations, reports from close others, and information

gathered through careful interviewing. Figure 2 provides a summary of five key areas requiring investigation.

A number of factors affect the initial presentation features, summarised in figure 1, of emotional, cognitive, physical, behavioural and existential symptoms. Screening for complicated grief potentially can be accomplished with a few key questions (Piper, Ogrodniczuk & Weideman 2005) but it must be remembered that symptoms can be the result of contextual factors, so the risk of false positives can be high. For example, loss of concentration might be related to preoccupation with new financial problems and not to depression. Note too, that the absence of overt signs of grief does not necessarily indicate the person is in denial and needs to get in touch with his or her grief. These assumptions can be unhelpful and the evidence has to be evaluated very carefully (Bonanno 2004).

<INSERT FIGURE 2 ABOUT HERE>

Pre-loss or predisposing factors need to be considered, e.g., having previously experienced severe traumas, or personal beliefs about death. However, their presence does not lead inevitably to complicated grief, again creating the possibility of false positives, so ongoing monitoring and assessment is essential.

To understand perpetuating factors, the quality of the relationship with the deceased and the degree of support among family and friends have to be explored. Where attachment was particularly close or intense, the person might initially feel overwhelmed by the possibility of living on alone. Low self-esteem, feelings of abandonment, a sense of emptiness, and despair might be present. Ambivalent relationships might mean the person feels intense guilt and is preoccupied with regret over what was said and done, or not done. Positive aspects of the relationship might

be denied or minimised, or the loved one idealised and the self denigrated. A sudden death has a very different impact from the passing of a person who has been frail for some time. A parent might find it hard to let go of a relationship with a dead child and resent being told by well-meaning people that she should 'be strong' and that she will 'get over it'. This also might contribute to complications.

The circumstances surrounding the bereavement, or precipitating factors, have to be carefully assessed. For example, an unexpected or accidental loss can be traumatic. Feelings of numbness, unreality and disbelief can be combined with shock, even terror. Where death is associated with stigma, such as suicide or resulting from AIDS, feelings of shame and social humiliation might predominate. The person might feel ostracised by friends and relatives, and avoid social contact, thus creating a self-fulfilling prophecy, further limiting opportunities for social support.

Hence, it is also important to assess the extent and quality of the person's social, cultural, and spiritual support post-bereavement. These can be protective factors, allowing the person to work through a relatively uncomplicated grief process, or they can serve to perpetuate and complicate the grief. Even if the person had many personal resources and enjoyed good social relations within a close family network, the event can lead to isolation and a reduction of social support, straining family functioning. This all requires careful assessment, including the extent of practical resources, such as access to government services.

Many techniques can be utilised to assess responses whilst also facilitating grieving. Genograms can help summarise information and provide visual images of the issues assessed. They can form the basis of further exploration and elaboration in counselling sessions. The meaning reconstruction interview can help a person explore

the emotional impact of loss (Neimeyer 2002). Linked with tasks such as keeping a personal journal, it can help clarify and integrate the experiences arising from the loss.

Another way to conceptualise grief assessment is to consider the framework provided by Maslow's hierarchy of needs (Table 2). Relevant questions raise increasingly complex and abstract issues, moving from crisis intervention to ensure physical safety in the early stages, through to aspects such as existential questions later in the process. This approach can be combined with other suggestions above to provide flexible, responsive support for grieving individuals, with referral to specialist services if it is deemed necessary.

<INSERT TABLE 2 ABOUT HERE>

Management of Grief Reactions

Helping patients with normal or uncomplicated grief

The complexity of presentation and the uncertain course of resolution place extra demands on anyone facilitating the process of grief resolution. A surviving partner, for example, burdened with grief, might feel overwhelmed by responsibilities of also managing the household, administering the deceased's estate, and caring for others in the family who are grieving. Practical problems may appear easier to deal with and be more pressing than the unfinished business of personal grief. Feelings might go unacknowledged and behaviour might swing from flat denial of the pain to strong experiences of anger and frustration. Effective facilitation therefore calls for appropriate communication skills (see Table 3). The aim is not achieve recovery (Stroebe et al. 2001). Rather, it is to ensure that individuals receive appropriate support while they experience and express their grief in their own manner. They will

usually find ways of coping with the changes, transform their relationships with the departed person, regenerate existing relationships, develop new ones, and maintain their own health and well-being during the transition to a new view of self, the world, and the future (Neimeyer 2006). In keeping with the emphasis on depathologising normal grief reactions, much of the support can be community-based, providing easier access to services for those who wish to use them. In Australia, for example, community organisations such as the National Association of Loss and Grief provide a range of information and referral services aimed at strengthening the community's capacity to respond meaningfully to people's needs.

<INSERT TABLE 3 ABOUT HERE>

With uncomplicated grief, these communication skills provide a framework for facilitating the grief process. They help balance the well-intentioned but frequently disempowering messages that others give the bereaved. For example, it is not true that life prepares us adequately for loss. Nothing, not even previous loss, fully prepares us. Exhortations to 'pull yourself together,' advice along the lines of 'learn to let go', or reassurances that 'you'll soon get over it,' might be well meant but are not helpful to the bereaved as they will often be perceived as judgemental. Bonds with the deceased may or may not be relinquished or strengthened, depending on the needs of the individual (Stroebe & Schut, 2005) It is only by experiencing grief that we can come to terms with loss. A bereaved person needs to interact with others who are empathic and understanding of their suffering; accepting them and being prepared to listen in a constructive manner can contribute to their adjustment.

Placing a time limit on grieving is similarly counter-productive. Many will grieve for a long period and no ideal time frame can be imposed on the process

(Carnelley et al. 2006). As noted, while the phases of grief can be a helpful heuristic, there is no support for the view that fixed stages need to be completed within a set period and it is unhelpful to suggest that people need to move on (Maciejewski et al. 2007). While it is increasingly realised that some survivors accept the loss with little questioning, many take more time to work through their complex feelings. Showing patience and tolerance is a critical part of management. Rather than needing encouragement to 'let go' or 'seek closure', they need support as they attempt to create new meaning in their lives (Neimeyer 2006). Grieving individuals will benefit from help in developing new interests and new friends, as they strive to complete the task of transforming the former relationship and revising their world-views.

Rather than consider grief as a set stage process, it is more useful to think of it as several broad, overlapping phases, noted earlier. They do not occur in a fixed order and progress is rarely simple. People may edge forward in a faltering manner, typically interspersed with outbursts of emotions such as anger and loss of meaning. Emphasis can be placed on the positive, adaptive aspects of grieving instead of concentrating on reducing loss-oriented negative emotions (Stroebe et al. 2001). Within these phases, four broad tasks of grieving can be identified:

Accepting and acknowledging the loss

Initially the importance of the loss may not be accepted. Individuals may report that events seem unreal and describe feeling numb and shocked. It may take a few days for reality to sink in. Common responses include withdrawing, being angry or crying and non-communicative. For example, a woman who lost her daughter in an accident three months earlier spent most nights awake, agonisingly studying family photographs and expecting her daughter to return, ending the mother's living

nightmare. The reality of the loss and its irreversibility first has to be absorbed before healing could begin.

Assimilating the loss

Once the initial impact has subsided, the person may become preoccupied and complain of intrusive thoughts, anxiety and restlessness, difficulty sleeping, other physical symptoms including loss of appetite, digestive problems, and fatigue. They may feel anger, guilt, and strong identification with the lost loved one, even reporting they have seen or heard the person. A depressive response on the anniversary of the loss can occur. This phase cannot be hurried or closed prematurely as the person comes to grips with the loss of the deceased.

Accommodating the loss

Recovery is marked by creating a renewed identity, making lifestyle changes and planning for a future without the physical presence of the lost one, even though emotional ties remain. Gradually individuals take charge of their lives and resolve the loss through activity, readjustment to old roles and development of new ones.

Transforming the loss

As the person starts to emerge from preoccupation with the lost one and a past that is gone, opportunity for revising one's life philosophy may emerge. Questions about the meaning of life and spiritual understandings can come to the fore. Life will probably never be the same again, and it is important to acknowledge that. Many people grow significantly as human beings after experiencing loss and grief. If the opportunity comes for them to explore these issues, they should be encouraged to grasp it.

Helping people with complicated grief reactions

Aspects of complicated grief reactions such as depression and anxiety may need to be treated before grieving can be properly facilitated (Zisook 2000). Treatment recommendations for depression accompanying complicated grief include the combination of tailored cognitive behaviour therapy, incorporating procedures such as counter-factual thinking, exposure techniques, and activity scheduling, together with appropriate antidepressant medication. In some cases, in-patient care might be required, or family-focused therapy recommended (Kissane et al. 2006). Evidence-based treatment for complicated grief reactions, in the form of a modified version of Interpersonal Therapy, is also now available (Shear, Frank, Houck & Reynolds 2005). Specialist advice is invaluable and appropriate referral should be considered.

Conclusion

Loss of important relationships, or bereavement, usually produces intense grief reactions. Recent studies have confirmed that most people's experience will be relatively uncomplicated and will resolve with time, yet they will generally benefit from appropriate support and encouragement. Effective communication helps facilitate the process of grieving. Some patients, however, will be at risk of complicated grief reactions and can develop significant co-morbidities, including major depression and anxiety disorders. Distinguishing these problems from uncomplicated grief reactions requires careful multidimensional assessment. Appropriate intervention and management, coupled where indicated with referral to specialised professional assistance, helps patients achieve better resolution of their grief reactions and improve their quality of life.

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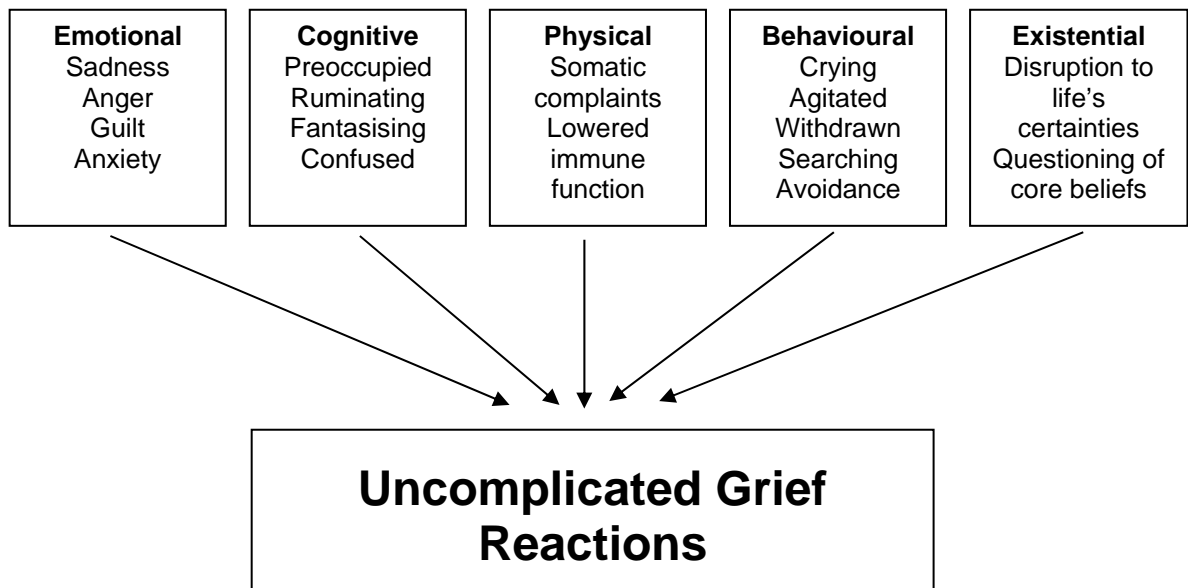


Figure 1: Multidimensional aspects of Uncomplicated Grief Reactions

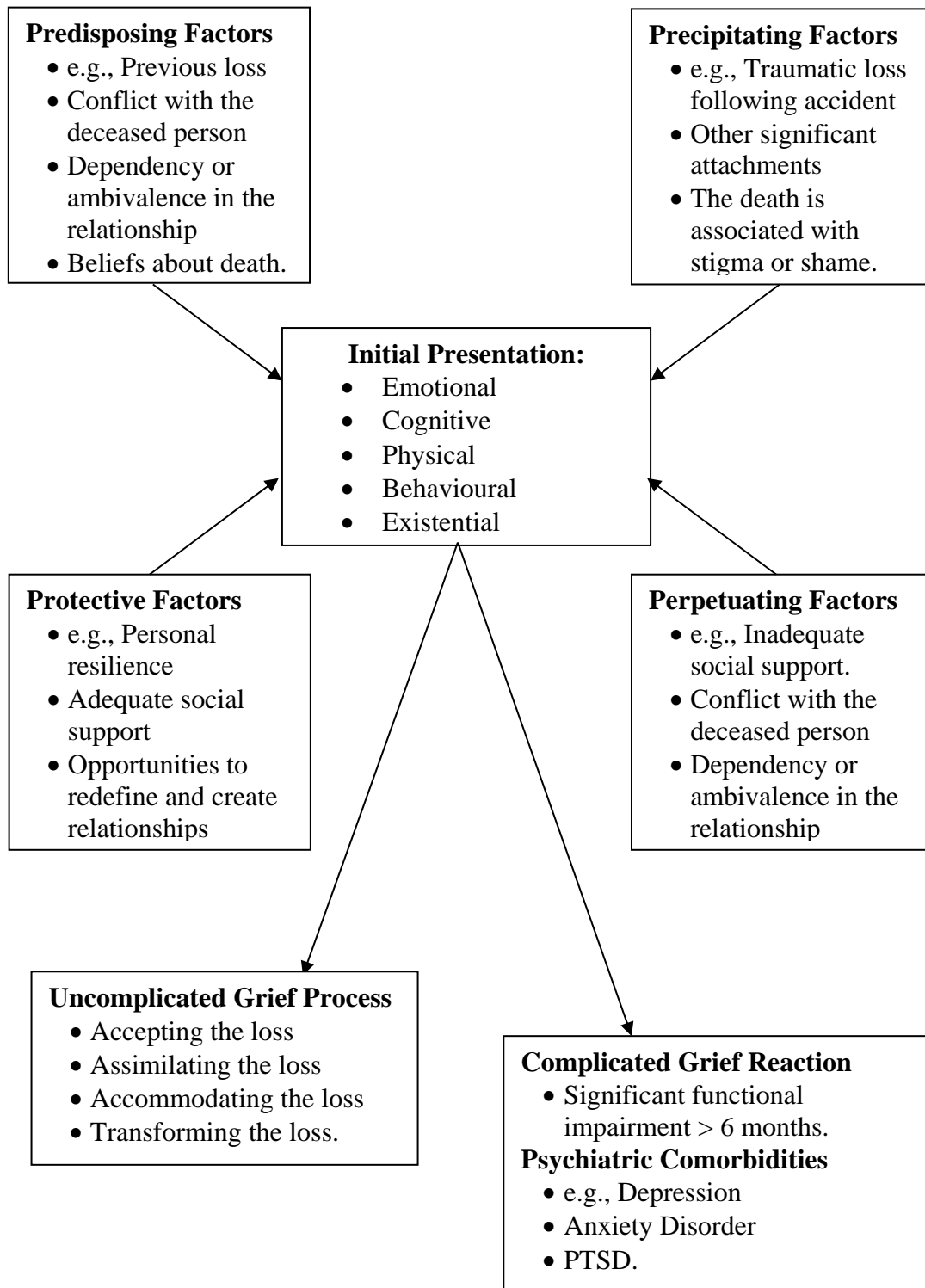


Figure 2: Assessment of Grief Reactions

Table 1: Some risk factors associated with complicated grief

Pre-loss

- Pre-existing mental health problems or few adequate coping mechanisms
- Children and adolescents, young spouses and older people in long-term relationships
- Lack of knowledge and information about death
- Previous experience of trauma and loss or multiple stressors
- Conflict and difficult relationships between the person and the deceased

When Loss Occurs

- The loss is the result of violence, trauma or accident, e.g., suicide, accident
- Others are unable to offer support and comfort for whatever reason
- The person died from an inherited disease or suffered a long illness
- The death is associated with stigma, or shame, for example, AIDS.

Post-loss

- Inadequate family or community supports or physical and emotional care
- Traumatic reminders, anniversaries and other significant events
- Secondary stresses that seriously disrupt family functioning
- Further losses or bereavements

(Adapted from Aranda and Milne, 2000)

Table 2: Bereavement assessment and Maslow's hierarchy of needs

Level of need	Thematic question
Physiological needs	How are your eating, drinking, sleeping (etc.) patterns?
Safety needs	Are you in any way concerned about your own welfare (e.g., any thoughts about joining your loved one?)
Belongingness needs	How are things with your partner and children? With other family members?
Esteem needs	Are you still able to pursue your work roles, your hobbies, etc., with the same interest?
Self-actualisation needs	How have these events affected your philosophy on life? Is it still worthwhile?

Table 3: Effective communication with grieving people

1. Acknowledge that grieving involves pain and misery for the bereaved. Help them identify and express these feelings by asking open-ended questions, for example, 'How has the death of ... affected you?'
2. Provide support and encouragement, as well as practical problem-solving contributions despite being troubled by your own sense of helplessness.
3. Prepare for strong, often volatile, reactions that may be directed at you. You may feel frightened or angry but calm, assured, non-judgemental responses can help the bereaved deal with their reactions better.
4. Take the perspective of the grieving person and maintain your empathic understanding. Even well intended questions can be counter-productive, for example, 'Surely you're feeling better today?'
5. Show your genuine concern and caring without being patronising or sounding as though you know best, for example, 'You should be getting over this by now.'
6. Refer on if your personal needs threaten to interfere with the process.
7. Stay non-judgemental and reflect feelings, especially early in the process, as attempts to explain the loss will usually be met with resentment or rejection.
8. Encourage them to experience and process the painful symptoms and avoid suggesting they have to feel better 'for the sake of others' or similar reasons.
9. Recognise and acknowledge the gravity of the situation for the person.
10. Nurture hope by normalising the process, while acknowledging the uniqueness of the person's response, and holding expectations that the person ultimately will accommodate the loss and that the pain will subside.