

BEREAVEMENT ASSESSMENT IN PALLIATIVE CARE – IDENTIFYING THOSE ‘AT RISK’

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Abstract: Bereavement care is well established as an essential element of palliative care. However, whether or not there is value in risk assessment tools to predict bereavement outcomes is open to debate. Members of multidisciplinary palliative care teams and nurses in particular are encouraged to provide high quality physical, psychological, social and spiritual care to patients and their families/carers, care that should include bereavement care. This article offers an analysis of traditional and contemporary bereavement theory, considers the use of a risk assessment tool to enable health professionals to make decisions as to whether an individual may be at risk of a complicated bereavement.

Keywords: Attachment, Bereavement, Grief, Risk Assessment, Palliative Care

Introduction

Society today continues to deny and fear the reality of death. It is suggested that death is swept under the carpet so that people can distance themselves from a frightening and uncomfortable subject but it remains a universal fact that 100% of all people will die (Parkes, et al., 1997). Bereavement is not a new phenomenon. Rituals and practices marked the change from savagery to barbarism as humans began to illustrate a concern for the dead (Payne, et al., 2000).

This article compares and analyses the development of models and theories of bereavement, and examines how family systems can influence bereavement assessment within palliative care. It has been found that grief can be an expression of many different reactions to social, psychological, behavioural and physical issues. Gender, age and culture can all have an affect on how an individual copes with grief (Jacob, 1993, Penson, et al., 2002). By considering these factors and developing an increased knowledge and understanding of bereavement, healthcare professionals can identify individuals who may be at risk from developing complications at an early stage.

Caring for individuals and their families prior to and following the death of relative or friend can be very stressful for healthcare professionals and can cause them to question our their beliefs and attitudes. This article will explore the benefits bereavement assessment can have for healthcare professionals in their aim to provide the highest standards of care.

Models of Grief

Relationships / Attachment / Moving on

One of the most influential theories of loss is by Freud (1917). Freud described grief as a series of stages that the person must go through. However, if the individual is unable to progress through these stages then difficulties may occur (Evans, 1994). Freud argued that the deeper the relationship between two people the greater degree of attachment. Therefore grief work involved severing the bonds with the deceased so that new relationships could be formed. He also believed that childhood experiences could have a profound effect on how an individual copes with grieving as the formation of our human personality occurs within the first five years

of life, and can shape how social relationships are developed in the future (Freud, 1925).

The importance of relationships and attachment in understanding how individuals experience bereavement was further developed by Bowlby (1980) who proposed that attachments are formed early in life between the child and the parent in order to feel safe and secure, and to survive. However, if this attachment is threatened, it can lead to intense anxiety, despair and emotional detachment e.g. children who had lost something special might cry, shout and have tantrums so that it is brought back. Bowlby claimed that in adult life the same mechanisms are used to attempt to bring back their loss (Payne, Horn and Relf, 2000). His four-phase model of grief includes:

- Shock and numbness
- Yearning and searching
- Disorganisation and despair
- Reorganisation.

Bowlby firmly believed that if the phases of grief were worked through, the risk of complicated grief would be lessened for each individual, as safety and security was reintroduced back into their lives (Payne et al 2000, Evans 1994).

The five-stage theory of dying of Kubler-Ross (1969) was initially developed for terminally ill people but now tends to be used for people following bereavement (Payne, Horn and Relf, 2000)

- Denial
- Anger
- Bargaining
- Depression
- Acceptance.

Although a well established and credible model it has been widely criticised over recent years for being inflexible, and linear with the critics believing that not all individuals will progress through the stages in a set pattern. Copp (1998) however concedes that the model did provide an orderly structure for professionals to follow.

Worden (1991) applied a *task* approach rather than *phases* to explore patterns of grief stating that

mourning is a process that has to be worked at. There are four tasks to his model:

- To acknowledge the death both emotionally and intellectually
- To experience the pain as it must be worked through or it will manifest at a later stage
- To adjust to life without the deceased
- To reinvest in new relationships and move on

Worden suggests that the person experiencing grief needs to move through all of the tasks, not necessarily in any order, if a complete adjustment is to be made. This differs from the other traditional models explored within this article, where a specific pattern is recommended if grief was to be resolved. Worden found that death can have an impact on the person's beliefs, values and assumptions and this can then lead to a loss of direction or purpose in life. He also introduced a more holistic approach where the emphasis is placed on the social, behavioural and cognitive aspects of grief.

This offers a useful framework to follow when aiming to provide the highest standard of care for the whole family. However there are many issues that need to be considered when exploring family grief. Open family systems where people are more able to express and share feelings tend to cope better with grief (Parkes, 1998, Riches and Dawson, 2000). Bereavement can affect how each family member relates to each other as changes in roles, routines and communication can disrupt the family equilibrium. Assessment of their needs at an early stage is therefore essential if areas such as coping strategies, stability, relationships and cultural issues are to be identified.

Recent theoretical frameworks

Walter (1996) devised a biographical model that challenges traditional theories on the emphasis of working through emotions and then eventual detachment from the deceased. Walter claimed that it is important to talk to others about their loss so that past relationships are carried forward into their ongoing lives. He believed if the bereaved 'bring the deceased with them': continuing their memory of the deceased, it could enable the bereaved person to move on (Payne, Horn and Relf, 2000, Stroebe, 1997). This model shifts the focus from the process to the social and interpersonal realities of individual

grief experiences. However, Stroebe and Schut's (1999) Dual Process Model introduces a new concept which looks at oscillation between coping behaviours i.e. being able to move between *loss-focused* activity that focuses on the impact of the loss and *restoration-focused* behaviours focusing on new roles, distractions and life changes. They believe if the individual can work between these two forms of activity, if they confront as well as avoid the patterns of grief, then adjustment will occur. However, the circumstances of the loss, and personality, cultural and gender factors need to be considered for each individual.

From exploring the more recent and traditional theoretical frameworks a progression and development of theory and practice is evident. While criticisms can be made of the more traditional phase and task models their process is useful if blended with the more recent models that focus on the family system and individual coping styles.

Bereavement Risk Assessment

Bereavement risk assessment in specialist palliative care (hospice care) is not an option; it is a mandatory clinical standard. The main family/carers of dying patients should have their bereavement needs assessed and addressed (CSBS, 2002). However, how that assessment takes place is open to discussion.

While the theories and models above give insight into the process of bereavement and can help us recognise and understand bereavement as a 'normal' process there will be those 'at risk' of a complicated bereavement. How do healthcare professionals identify and assess those at risk, and what action is taken following the assessment?

One approach is to use a risk assessment tool which enables healthcare professionals from their knowledge of the patient and their family/carers to identify those who may be at risk. However to make an accurate assessment it is important to understand that the grieving process can commence from the time of diagnosis (Egan and Arnold, 2003).

Anticipatory grief is a recognised process that occurs prior to the patient's death. It can be a combination of losses that have occurred in the past, those being experienced in the present and the an-

icipation of those that will occur in the future. The effects of loss from diagnosis and treatment through terminal illness and after death, can form a pattern of grief. Therefore associated emotions such as anger, denial, fear and depression can be experienced from a very early stage (Costello, 1999, Evans, 1994). Experiencing anticipatory grief has been found to have some benefit in that it can provide time for the family to accept, prepare and adjust to the bereavement (Egan and Arnold, 2003). If assessment of the needs of the family start before death, ideally from the time of diagnosis, healthy adaptation to bereavement is more likely to occur. In addition it is important to assess the history of previous losses, which should include divorce, separation and other life changing events as recent losses can open up past emotions and feelings.

Other relevant factors when assessing those at risk of complicated bereavement are the mode of death and the intimacy of the relationship, both of which can lead to more severe and prolonged grief. As Parkes (1998) also points out a small number of bereaved people are at risk of a variety of disorders which can arise from bereavement such as clinical depression, anxiety and stress disorder. In addition bereavement is also associated with an increased suicide and death rate. However rare, all these issues need to be taken into account when assessing an individual's risk of a complicated bereavement.

Experience suggests that healthcare professionals' instinct and experience can be tuned to identify those at particular risk. However, do you rely on instinct or do you use an assessment tool that harnesses that instinct and gives a measure across differing healthcare professionals' assessment? In the author's experience a written bereavement risk assessment is a useful way of assessing the needs of the bereaved and in identifying those at particular risk of a complex bereavement. However, the key in creating an effective assessment tool is to ask meaningful questions of the healthcare professional, questions which direct and clarify their interpretation of the psychological and social issues of the bereaved person and also the circumstances of the illness and death. In considering these questions an assessment can then be made as to whether people might be expected to experience a normal bereavement or be 'at risk' of a more complicated bereavement.

A sample risk assessment is included at figure 1 below:

Figure 1		
Risk Assessment Questions (Please Circle Yes / No)		
Psychological issues: -		
• Has difficulty in believing the patient is seriously ill or is dying		Yes / No
• Has pre-existing or new psychiatric/psychological problems		Yes / No
• reactions to impending loss are intense (distress, anxiety, withdrawal)		Yes / No
• Was very dependent on patient or vice-versa		Yes / No
• Has intense anger or causes undue friction with patient		Yes / No
Social issues: -		
• Has other concurrent losses, stresses or illnesses		Yes / No
• Has little or no social or family support		Yes / No
• Has young children/other dependents		Yes / No
• Is young themselves (child/adolescent)		Yes / No
• Works in Healthcare		Yes / No
Circumstances of the illness and death: -		
• Was absent at death		Yes / No
• Reaction at death was absent or extreme		
• Patients death was felt to be untimely		
• The illness was very short, very long, or very distressing		Yes / No
• The patient was young		Yes / No
High Risk (9-15)	Medium Risk (5-8)	Low Risk (1-4)
Adapted from (Jacob, 1996)		

Risk assessment forms are designed to identify people who may develop complications following bereavement. In the above example, which in practice is used in a hospice with an in-house bereavement service, Low and Medium risk are regarded as 'normal' and the individual is followed up by a letter offering 'opt in' support six to eight weeks after the patient's death. However those identified as high risk are followed up by phone call. However it is entirely up to the individual if they want to use the service.

There is clear evidence that risk assessment is an important element of bereavement care. However, the validity of any assessment can be questioned when you consider the short time most healthcare professionals have in contact with patients and their family carers, the inevitable individual variations in beliefs and experiences of the healthcare professional making the assessment, and at which point the assessment is made: before the death, at the

time of death, or a few days later when the health professional has time. A further factor to consider is what will be done with the information? Is there value in completing a risk assessment if the bereaved are to be referred to an outside agency that doesn't accept referral by a third party insisting instead on self-referral?

Conclusion

From the literature and theories explored above it is clear that bereavement theory and its understanding has moved from a psychiatric disorder which can be assessed and cured, to a more individual understanding of and individual process that for most people will be 'normal' while for some will be more complex. While there is still merit in the phase and task models their adaptation to models that include the individual, interpersonal and sociocultural factors has been a positive development. Analysing the different models and theories con-

firms that grief is a combination of many factors and can affect emotions, behaviour, physical health and social relationships. Variables relating to life-span perspectives i.e. early childhood experiences, why and how people form relationships and family composition can all affect how one grieves.

An understanding of the various models of grief and bereavement theory can help healthcare professionals gain a better understanding of how grief can affect each individual differently whether it is prior to or following death and to recognise complications if they should occur. While experience would advocate that a bereavement risk assessment is carried out, whether it is a written assessment or not is open to debate. However, perhaps the most relevant question is what type of bereavement service will be offered to the bereaved. Is it an in-house service or an external agency? Only by answering this question will the type of a risk assessment used be relevant.

Within specialist palliative care the main aim is to provide the highest standard of care for the patient and their family/carers. That care includes bereavement care as a mandatory clinical standard, it is not an 'option'. That bereavement care should be a part of all health care is a reasonable expectation. However, how it is structured and resourced is a different question for another study.

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