

Foundations in palliative care

A programme of facilitated learning for care-home staff



Bereavement care

Facilitator workshop guidelines

Supported by



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Programme

Workshop 1 Understanding bereavement

1 hour 30 minutes

Session 1.1	Introduction	10 minutes
Session 1.2	Pairs activity: participants' experience of bereavement	10 minutes
Session 1.3	Feedback	20 minutes
Session 1.4	General information: understanding grief	15 minutes
Session 1.5	Discussion: models of grief and older people	20 minutes
Session 1.6	Discussion: trigger statements 1	10 minutes
Session 1.7	Closing remarks	5 minutes

Workshop 2 Grief in a care home for older people

1 hour 30 minutes

Session 2.1	Introduction	5 minutes
Session 2.2	Discussion: who grieves in a care home?	10 minutes
Session 2.3	Small-group activity: hidden grief in a care home	15 minutes
Session 2.4	Feedback	10 minutes
Session 2.5	Audio session: the grief of staff	30 minutes
Session 2.6	Discussion: trigger statements 2	15 minutes
Session 2.7	Closing remarks	5 minutes

Workshop 3 Supporting bereaved people

1 hour 30 minutes

Session 3.1	Introduction	5 minutes
Session 3.2	General information: categories of support	15 minutes
Session 3.3	Discussion: guidelines for supporting relatives	15 minutes
Session 3.4	Small-group activity: drawing up guidelines	15 minutes
Session 3.5	Feedback	20 minutes
Session 3.6	Discussion: respecting and remembering the dead	15 minutes
Session 3.7	Closing remarks	5 minutes

General facilitator preparation

- Ensure that all participants have successfully completed module 1
- Familiarise yourself with all three workshops in this module
- Make sure that all the participants know the date, time, and place of the first workshop
- Read the further reading given at the end of the module (*The process of death and the nature of relationships*). This is a research-based discussion of the process of death and the nature of relationships in care homes for older people
- Read the facilitator texts for each workshop
- On the day, check that the room is ready and that there are enough chairs, and that they are set out in a semicircle or other informal arrangement
- Check that refreshments are available, if appropriate
- Check the equipment (flipchart, pens, CD player)
- Make sure that you will not be interrupted – put a sign on the door, if necessary ('Training in progress')

Workshop 1

Understanding bereavement

Aim

To reflect on the feelings associated with grief.

Facilitator preparation

Before the workshop you will need to:

- Remind participants of the date, time, and place of the workshop, and ask them to bring a pen for making notes
- Study the facilitator guidelines and the following facilitator texts:
 - Facilitator text 1.1 (*Understanding grief*) – a discussion of the stages of grief from which most models of grief were developed
 - Facilitator text 1.2 (*Bereavement in older people*) – a general overview of bereavement in older people with a discussion of the appropriateness of models of grief to older people
 - Facilitator text 1.3 (*Alternative approaches*) – an exploration of other models of grief
 - Facilitator text 1.4 (*The effects of grief on physical and mental health*) – a look at the evidence that bereavement can cause ill health
- If necessary, make notes for the activities on the flipchart – keep them simple and clear
- Bring the flipchart notes from module 1, workshop 2, session 2.3, which listed the feelings connected with loss of home. You will need them in session 1.3 of this workshop
- Make sure that you have enough copies of the *Participant's workbook* for module 4
- Bring the ground rules agreed in module 1

Facilitator guidelines

Session 1.1

10 minutes

Introduction

Welcome participants and, if necessary, introduce yourself and ask them to introduce themselves to the group.

Display the ground rules agreed in module 1. Although everyone in the group will have completed module 1, they may not have done so together. Therefore, you may need to explain that the ground rules were agreed by another group and they can be changed. Ask participants if they are happy with the ground rules and if they want to make any changes. This will give everyone a chance to contribute to the ground rules for this module. If participants agree new ground rules, ask them to write them down on p. 2 of their workbooks. You will need to keep the new ground rules to display in workshops 2 and 3.

Direct participants to p. 3 of the workbook and explain the aims of the workshops in this module, which are:

- Workshop 1 – To reflect on the feelings associated with grief
- Workshop 2 – To consider who grieves in care homes for older people
- Workshop 3 – To assess the support needs of residents, relatives, and staff when someone dies in a home

Remind participants that the purpose of the workshops is to draw on their experience as well as to explore new ideas and issues. The workshops address painful issues at times and participants should not feel obliged to share painful feelings unless they feel comfortable doing so. Also remind them that, although they should support each other, the workshops are educational not therapeutic sessions.

Direct participants to p. 4 of the workbook and run through the programme and timetable for the workshop. Explain that, as in the previous workshops, participants will be working in pairs and in small groups, as well as taking part in discussions with the whole group.

Session 1.2

10 minutes

Pairs activity: participants' experience of bereavement

Ask participants to pair up and share with each other an experience of bereavement but not one related to a resident. Ask them to note down in their workbooks (p. 5):

- The feelings associated with the bereavement
- The responses of other people (friends, family members, acquaintances, work colleagues) to their bereavement

Session 1.3

20 minutes

Feedback

Feelings associated with bereavement

Remind the group of the work they did in module 1, workshop 2, session 2.3 on the feelings associated with loss of home. Display the flipchart notes from that session. Ask the group to discuss the similarities between the feelings they noted in the earlier session and those they have just identified in connection with bereavement. Add any new or different feelings to the sheet.

Members of the group will probably mention feelings of loneliness, disbelief or denial, pain, numbness, and exhaustion, although not all people experience such strong feelings. During the discussion encourage participants to consider why they felt the way they did.

Other peoples' responses

Next, ask participants how other people responded to their grief. Write the responses on the flipchart. They are likely to include:

- Kindness
- Willingness to help
- Rejection
- Embarrassment
- Unwillingness to talk about the bereavement
- Short-term sympathy

Some members of the group might be part of a community that has specific ways of dealing with bereavement, in which case, this would be a good point for a short discussion on cultural aspects of bereavement, although this issue is addressed again in the following workshops. Whichever cultural traditions participants follow, remind them that it is important to be aware of other traditions with different perspectives on death, and not to judge them.

Session 1.4

15 minutes

General information: understanding grief

Direct participants to p. 6 of the workbook (*Stages of grief*) and work through the three stages with them. Use your notes on facilitator text 1.1 (*Understanding grief*) to help you draw out the strengths and weaknesses of each stage. Refer to the Kübler-Ross model of loss discussed in module 1 (workshop 2, session 2.6), which included similar stages. If necessary, check participants' understanding of the terms 'bereavement', 'grief', and 'mourning'. Bereavement is the state of being robbed of a close and meaningful relationship; grief is the emotional response to that loss; and mourning is an outward expression of grief that has social and cultural components.

Teaching points

Do not spend too long debating the pros and cons of each stage of grief as you need to move on to link the stages with the experience of older people in the next session. However, before you move on, make the following points:

- As in the Kübler-Ross model, grief is described in the stages model as following a fairly set pattern with recognisable stages going from initial shock and disbelief to eventual recovery and reorganisation. The attempt to describe stages of grief is an attempt to understand and describe human behaviour and find patterns and similarities
- Such models enable those who grieve to gain comfort from knowing that their experience is shared by others, and that their responses and feelings, however frightening, are not peculiar to themselves. This is perhaps the overall strength of the stages approach
- Setting up patterns of normal behaviour can exclude as well as include people's experience, and deny the uniqueness of the individual response. Indeed, some people appear not to experience or demonstrate any response to the death of someone close
- The weakness of this type of model of grief is that it provides too rigid a framework. It is prescriptive rather than descriptive. As a result, people might think that this is how they ought to feel even if they do not. Such models also put time limits on feelings. Defenders of the stages model argue that the stages do not necessarily follow on from each other or are expected to last for a set period of time. Another weakness is that the stages model was developed within western culture and may therefore not be appropriate for bereaved people from different cultures

Session 1.5

20 minutes

Discussion: models of grief and older people

Ask the group to discuss the appropriateness of the models of grief they explored in the previous session to residents in the care home. Use your notes on facilitator texts 1.2 (*Bereavement in older people*) and 1.3 (*Alternative approaches*) to lead the discussion. If participants wish to make notes during the discussion, space is provided on p. 7 of the workbook.

Discussion points

Participants are likely to have strong views in relation to this topic. They are also likely to focus on the last stage – recovery. If necessary, remind them that residents are probably not strangers to grief and many will have experienced the death of a spouse or other close relative or friend, and possibly even a child. Suggest the following points, if they do not arise in the discussion:

- The stages model described in on p. 6 of the workbook is perhaps more appropriate to sudden and unexpected deaths, when shock and disbelief

are likely reactions

- Many bereavements experienced by older people occur after a long period of illness and are therefore anticipated
- Enduring or rekindled grief occurs in some people (see facilitator text 1.2)
- The experience of multiple losses can exacerbate grief
- Feelings of relief at the end of a loved one's suffering can bring consolation. However, a long period of terminal illness can also cause a great many problems. For example, the sheer exhaustion of caring over a long period of time can take its toll on the mental and physical health of carers
- Proper leave-taking helps satisfy friends, relatives, and other carers that they have done everything in their power to ease the dying process. Saying goodbye can also bring comfort after the person has died
- Other models of grief, such as the Stroebe and Schut model (facilitator text 1.3), suggest that people move between stages and can go through more than one stage at a time. Thus, a bereaved person might experience a range of different feelings in any one day, including the occasional and unexplained wave of overwhelming sadness that appears to return people to the beginning of the process
- Walter's model of grief (facilitator text 1.3) emphasises talking about the dead person and reconstructing a common understanding. Walter suggests that this is more important than 'working through emotions'. This model might be particularly appropriate in care homes, where both residents and staff could benefit from talking about a dead resident and sharing anecdotes about them, thus breaking the silence that often accompanies death

Session 1.6

10 minutes

Discussion: trigger statements 1

Direct participants to p. 8 of the workbook (*Statements about older people and grief*) and give participants a few minutes to decide whether they agree or disagree with the statements and mark them accordingly. Make it clear that this is not a test; the questions were designed simply to stimulate discussion and there are no right or wrong answers. Go through each statement in turn and discuss why participants agreed or disagreed with each statement.

Discussion points

In the discussion ask the group to think about the statements in relation to the way they approach death and dying with residents.

Agreement with the first two statements ('Older people are more accepting of death' and 'The more losses you face the better you are able to cope') provides an excuse not to talk to residents about their fears and feelings associated with death and grief.

There is evidence to suggest that the third statement ('You can't die of a "broken heart"') is wrong and that, indeed, 'Widows cope better than widowers' (statement 4). Facilitator text 1.4 (*The effects of grief on physical and mental health*) suggests that older people, especially older men, are at an increased risk of heart attack in the first 6 months of bereavement. The risk of suicide is also increased.

Session 1.7

5 minutes

Closing remarks

- Thank everyone for taking part in this workshop
- Point out that the workshops will help them build on their life skills and experience
- Agree the date, time, and place of workshop 2, and ask participants to write the information in the box provided on p. 9 of their workbooks. Remind them that it will address aspects of grief in care homes
- Finally, suggest that participants record their thoughts about the workshop and how it might affect their practice in their workbooks (p. 9). In particular, ask them to write down the most important lesson they have learnt. For instance, they might feel more aware of the losses residents have suffered in the past and be more open to discussing them. Also, remind them to bring their workbooks to the next workshop

Facilitator text 1.1

Understanding grief

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 4, *Bereavement: Private Grief and Collective Responsibility*, which are reproduced by permission of The Open University.¹

Stages of grief

Grief has been likened to a developmental process with recognisable stages or phases going from initial shock and disbelief to eventual recovery and reorganisation. This approach to understanding grief is not unlike that of Elisabeth Kübler-Ross. The criticisms of these approaches to grieving are that they provide too rigid a framework; that they can be prescriptive rather than descriptive; that people will think that this is how they ought to feel even if it is not how they do feel; that they put time limits on people's feelings.

Defenders of the stages model will counter that the stages are not necessarily sequential or time limited, and that people frequently oscillate between stages and also can be in more than one stage at any one time.

Perhaps the most problematic stage is the last one, the end part of the process: acceptance, in relation to dying; recovery, in terms of grieving. The stages of grieving identified by a number of authors, are summarised by Raphael in three main stages:²⁻⁵

Shock and denial

Almost all authors agree that the initial reaction to the loss of a loved one is shock, numbness or disbelief. Bewilderment, disorientation and a loss of perspective characterise this first stage as well as a lack of energy and motivation. Most authors agree that this stage is relatively short-lived, ranging from a few days to a few weeks, although there is an increasing reluctance to put any time limit to any of these stages.

Pining

After the first stage there is a period of intense grief when the reality of the loss is faced, bringing with it feelings of pining for the dead person and a whole range of emotions, including guilt, anger, loneliness, and despair. During this second stage the person's life is very much dominated by the grief. This period, it is claimed, lasts for about a year.

Reorganisation and recovery

The bereaved person gives up any unrealistic hopes of recovering the loved one and starts to adjust to a world without him or her. This is stage three – recovery.

Advantages and disadvantages

Unfortunately, this progression has been interpreted rather rigidly as stages through which all bereaved people should go, and sometimes a timescale is even attached to it. Instead of being a descriptive tool to help us understand some of the feelings that grief may bring, it becomes a blueprint for telling a bereaved person how they should react and is used as a measure of their progress. Understandably, many bereaved people have objected to their unique experience being moulded in this way and to being told how they ought to feel and behave. Others, because of religious or cultural traditions, will react in different ways, which may be defined by their own specific mourning rituals. The stages are only of value if they help people to understand some of their own feelings. For the bereaved person, who may feel bewildered by the intensity and strangeness of their own emotions after the death of a loved one, having some guidance on how they might feel can be comforting. Sharing experiences can be very helpful in reassuring the bereaved that they are not alone in their experience. On the other hand, if bereaved people are made to feel that they ought to feel and behave in a certain way, and in fact do not do so, they could be made to feel inadequate or 'abnormal'.

There is then a danger that these stages, which do resonate with many people's experience, will be interpreted as fixed sequences and, instead of reassuring someone that their feelings and behaviour are not uncommon, be interpreted as an indication of how someone should feel.

The evidence seems to suggest that people grieve in many different ways. Some show very few signs of intense distress while others are incapacitated by their grief. Some recover and reorganise their lives in a short time, others take longer. Some simply go on grieving but also go about their daily lives in a perfectly ordinary way.

References

1. The Open University. *Bereavement: Private Grief and Collective Responsibility*. Workbook 4, course K260. Milton Keynes: The Open University, 2001;13–15.
2. Glick L, Weiss R, Parkes C M *The first year of bereavement*. New York: John Wiley & Sons, 1974.
3. Gorer G. *Death, grief and mourning in contemporary Britain*. London: Cresset, 1965.
4. Parkes CM. *Bereavement studies of grief in adult life*. London: Penguin Books, 1986.
5. Raphael B. *An anatomy of bereavement: a handbook for the caring professionals*. London: Hutchinson, 1983.

Facilitator text 1.2 Bereavement in older people

This text is reprinted by permission of Sage Publications Ltd from a chapter in a book edited by Bond J, Coleman P, and Peace S entitled *Ageing in society* (©Sage Publications Ltd.).¹

Older people are likely to have encountered many losses as they age. Does this make it more or less difficult for older people to face bereavement in later life? Are losses cumulative in their effect or do people learn to deal with them better the more they have to encounter?

How we cope with bereavement in adult life is said, by some theorists, to depend on our ability as infants to cope with the 'separation anxiety' induced by the inevitable separation from the breast, in both a physical and metaphorical sense.^{2,3} On our success in creating an inner life to deal with this anxiety as infants depends our future ability to deal with losses that hurt. Other theorists following Freud focus on the need to test reality when facing major losses, to learn to accept the reality that the lost loved object is no longer there.^{4,5} This is necessary in order to release the energy invested in that attachment and re-invest it in new attachments. From these theoretical bases some pervasive and quite prescriptive models have been developed which have a lot in common with the Kübler-Ross stages model of attitudes to the loss of one's own life.

In so far as these models resonate with people's own feelings and experience they have the virtue of reassuring people that their painful and seemingly irrational behaviour is shared by others, that they are 'normal' and their behaviour is predictable. By the same token they also define others, whose behaviour and feelings do not fit into the model as 'abnormal' and sometimes 'pathological'. They therefore seek to mould individuals into a set pattern. That individuals vary in their reaction to loss is clear to anyone who encounters bereaved people. Can we discern patterns and what are the effects, if any, of age?

Parkes, a long-time advocate of the stages model of grief, has rooted his theoretical position in a great deal of empirical research, mainly concerned with the effects of the death of a spouse. His work has focused on widows and widowers and, although it is not always possible to differentiate the evidence on the basis of age, it does provide a rich source of data on the physical and psychological effects of grief.⁴ The pattern which was clearest to Parkes was that bereaved spouses experienced an initial stage of shock and numbness. This gave way to denial of the death when the widow or widower still felt the presence of the dead person, sometimes actually seeing them or hearing a voice. These feelings could be very disturbing to people because at some level they sensed they were irrational and fears of madness were not uncommon. When the widow or widower finally realises that the husband or wife does not exist in any earthly sense great anguish is felt, reality is painful and often quite disabling. Gradually, the pain eases and the person is able to focus on other things and rebuild his or her life. This final

stage of reintegration and reorganisation was often interpreted as meaning the beginning of a new relationship but the relationship is not necessarily with another person but with a new life in which the lost loved person does not figure. Only then can it be truly said that the person had resolved their grief. The estimated time it took to arrive at this stage of resolution has varied from 1–4 years. Parkes himself has, over the years, relaxed his position on this sequential stages model, feeling that not everyone necessarily should experience all the stages and certainly not within a set timescale.⁴ Nevertheless, this model has percolated into popular literature in a highly prescriptive way. It also guides much bereavement counselling although there are attempts, such as the 'grief wheel' model, to work with much more flexibility and recognise that the stages are not necessarily sequential.⁶

The stages model could be said to be more appropriate to reactions to sudden and unexpected deaths where shock and disbelief would seem inevitable. Many bereavements experienced by older people come after a long period of illness and have been anticipated. The question of whether such 'anticipatory grief' relieves the pain of the eventual grief has been the subject of much debate in the bereavement literature.⁷⁻⁹ It seems safe to say that grief which has been forewarned is less painful than grief which is sudden and unexpected.^{4,10} Feelings of relief at the end of a loved one's suffering can bring consolation. Proper leave-taking and the satisfaction that one had done everything in one's power to ease the dying process can also bring comfort. But there is evidence that a long and protracted period of terminal illness can cause a great many problems for the subsequent bereavement period.¹¹ The sheer exhaustion of caring over a long time can take its toll on the mental and physical health of the carer.¹² Very often older people cannot maintain the physical demands of caring for a dying person and have to allow their spouse to be taken into a home or hospital to die. This sense of failure can 'play on the mind' for many years after the death. There may be many instances when the carer felt they should have done more and, consequently, feelings of guilt can complicate their grief.⁴ Bowling and Cartwright in their study of older widowed people found that some of their respondents reproached themselves and wished they had done things differently.¹³ Some wished they had spent more time with the dead person, others that they had sought medical help sooner, some wished they had talked more about the impending death.

Being present at the time of death is very important to bereaved spouses. Of the widows in Bowling and Cartwright's study who had not been able to be present at the death well over half deeply regretted it. This, Bowling and Cartwright believe, could adversely affect their adjustment to their bereavement.

In the stages model of grief if the final stage of reintegration and reorganisation is not reached the grief is thought to be unresolved. The metaphor of a lesion is much used to describe grief, resolution of grief is akin to a healing wound. By implication a wound that does not heal becomes poisonous and festers, 'pathology' sets in. But, increasingly, a third outcome

to bereavement is being acknowledged where the wound does not heal but neither does it fester. It remains an unhealed wound. This has become known as 'enduring grief' and has been particularly recognised in the grief of parents who lose a child. Although they resume a normal life, possibly have other children, they never stop grieving for that child. Their grief does not poison their lives but neither does it diminish greatly. When interviewing older women I found that many of them had also never stopped grieving for their dead spouses 10 or 15 years after the death yet they led active and full lives.¹⁴

Another form of grief which I found amongst the women I interviewed was what can only be called 'rekindled grief'. What became clear when listening to these women who had lost their spouses many years ago and who had ostensibly 'accepted' the loss, was that the sense of loss of a partner could be reawakened and actually felt again if and when their circumstances deteriorated. It is not difficult to appreciate that if children and even grandchildren are grown up and are perhaps geographically inaccessible, if infirmity renders one housebound then that is the very time when one would most benefit from a close and special partner. Clearly, the quality of the actual partnership is important, but in its absence it is the absence which is painful.

It would be foolish to ignore the fact that many marriages and relationships are extremely unhappy, and that the death of one of the partners may release the other from a great deal of aggravation. Not everyone is sorely missed. But, even if the relationship had been thoroughly bad there are other losses to contend with, loss of social status, income and security all have to be dealt with. But it has been found that grief when there was a good deal of ambivalence about the relationship that is lost can be quite complicated because there is the guilt of actually feeling relief that someone has died.^{15,16}

Grief can be disabling and bereavement is always high on any list of potentially threatening 'life events'. Parkes' studies on bereavement provide an excellent review of the evidence of links between bereavement and mental and physical illness. He explores what he calls 'the broken heart' syndrome and asks whether people can actually die from grief.⁴ Mortality data indicate that widows and widowers have higher mortality rates than people of the same age who are married, but this is complicated because of remarriage and it is suggested that the fittest are likely to remarry. However, Parkes shows that the mortality rate for widowers in the first 6 months after the death of their spouse was 40% higher than the expected rate for men of the same age who were married. The evidence for widows is conflicting, a study by Mellstrom *et al* found a significant increase in the death rate amongst widows in the first three months after the death of their spouses but not after that.¹⁷

Parkes is satisfied that, in men, bereavement is linked to subsequent deaths from diseases of the cardiovascular system, but he is careful not to make direct causal links, instead he uses terms such as 'exacerbate' or 'precipitate'. What we know about the body's reaction to shock – raised pulse and blood

pressure, palpitations, sweating, and acute anxiety – make this a plausible theory.

Loneliness is one of the most serious problems identified by most older widowed people. About half of the widows in both Lopata's and Bowling and Cartwright's studies found loneliness to be a major problem for them.^{13,18} Depression also has been linked to bereavement in a number of studies.¹⁹⁻²¹ Although these studies are not age-specific, those focusing on older people have found that bereavement is a factor in depression in older people.²² An American study which compared younger and older widows, found that younger widows suffer more in the short term but that older widows have more long-term problems.²³ This same study also points out that low socioeconomic status makes bereavement more difficult. Sanders cites a study of a group of older working-class widows which found that a reduced financial state led to reduced social participation resulting in greater loneliness and anxiety. Another study went so far as to conclude that 'the negative impact sometimes attributed to widowhood derives not from widowhood status, but rather from socio-economic status'.²⁴ Older widows are one of the most impoverished groups in our society. Widowhood, especially for women, represents many losses, not only the loss of financial status. Dorothy Jerome mentions companionship, a partner in a world which is couple oriented and the loss of a sexual partner.²⁵ Four out of ten of the widows in Helen Lopata's study claimed to have a less active social life than before their spouses' deaths.¹⁸ Another problem identified by Lopata was the need to adopt new roles and this was particularly difficult for older widowed people for whom gendered role divisions had been fairly rigid before the death.

However, widowhood is not an entirely negative experience for women and, as noted earlier, they seem to fare better than widowed men. The gender composition of the widowed state has certain positive aspects for women, although only if they are still mobile and relatively fit. Because widowhood is almost the norm for older women they form a recognisable group, role models abound and there is no shortage of other widows to identify with. They can go on holiday together, join clubs together, and even dance together. Widowers on the other hand are a much more isolated type. They do not have a 'pool' of men in the same situation as themselves, but they do have greater opportunities to remarry, which many do, and it is the widower without a partner who seems most at risk. The impact of gender and socioeconomic status are clearly important to the way grief is experienced but there are other independent variables.

As with attitudes to death in general an important independent variable is the impact of religion and culture. Many bereaved people take comfort in the belief that they will somehow meet their loved ones again. A high proportion of the widowed in Bowling and Cartwright's study said they held a religious belief.¹³ They were all Christians and between a third and two-thirds of them felt that this had helped them to adjust to their bereavement. However, no difference was found on the adjustment scale used by Bowling

and Cartwright between those who felt that their belief had helped them and those who had no such belief, nor was there any difference in reported loneliness between these groups. Much of the debate about the effect of religious and cultural traditions focuses on the effect of mourning rituals on the experience of grief. There is a general assumption following Gorer that the apparent lack of ritual in contemporary western societies makes grieving more difficult.²⁶ Mourning rituals do provide a socially acceptable framework for grief, they allow people permission to weep openly and they provide milestones during the period of mourning to allow the bereaved a time to adapt gradually to the changes in their lives. But above all they ensure social support for the bereaved which should help prevent the loneliness and isolation felt by so many bereaved people. We have no research information to show whether the private grief of people whose culture or religion provides a set pattern of mourning is any different from the grief of those whose culture lacks such rituals. We are left with the difficult question, does the experience of sorrow match the expression of sorrow? Certainly in a cultural atmosphere which finds the expression of sorrow hard to deal with, those experiencing such sorrow will feel isolated and alone.

Another factor in bereavement which is thought to exacerbate grief is the experience of multiple losses, either at the same time, as in an accident, or over a short period of time. Older people frequently find themselves in the latter position. We have so far concentrated on the death of a spouse but other deaths may be equally, if not more distressing for older people, especially if they happen in close proximity. The deaths of siblings, friends, and contemporaries are, as well as reminders of one's own finitude, often a loss of links with the past or the loss of a valued confidant or companion. Female friendship in later life is often a lifeline for many older women and there is evidence that loss and grief when it happens in such circumstances is not acknowledged.²⁵ The term 'hidden grief' has been used to describe those who are not recognised as legitimate mourners where the emphasis is on familial ties.

Older people also lose adult children and grandchildren and their grief can be compounded by feelings of guilt that they are outliving their offspring. Compassionate Friends, an organisation which provides support to those who lose a child, claim that grandparents' needs are often not acknowledged. Grandparents can, in effect, suffer a double loss because their own offspring, the parent of the dead child, may withdraw affection and distance themselves.

Compassionate Friends is one of many organisations, mostly run by voluntary but trained counsellors who offer help to bereaved people. CRUSE is perhaps the best known and has a national network. Originally set up to support widows, CRUSE now offers help to anyone bereaved and it runs many group therapy sessions. It has been reported that only a small percentage of those seeking help are very old.²⁷ The reasons are not known. Maybe older people have few expectations of receiving help, maybe they are unaware of what is available or of how to negotiate help. Maybe they do not feel the need for

help or maybe they have all the support they need. In the absence of any reliable data on the subject we can only assume that any of these probabilities are possible.

Conclusions

For a variety of reasons the subject of ageing and death and dying has received relatively little attention. Because death is the outcome of the dying career there are certain peculiar difficulties attached to researching the subject. As Marshall points out 'there are no graduates'.²⁸ Although the greater prevalence of resuscitation techniques has led to a growing number of claims of 'near-death experiences' these have been explained by the raised levels of carbon dioxide in the brains of people who lose consciousness.²⁹ For most of us death remains a mystery. Some of us fear it, others accept it. On the whole older people seem more inclined to accept it, perhaps because as the poet Philip Larkin observed: 'Death is no different whined at than withstood'.³⁰

The process of dying, on the other hand, is different. We can help to relieve pain and suffering whether this is physical or emotional. While we may find it hard to conceive of the process as ever being 'good' clearly the manner of some people's dying is better than others. Striving to improve the quality of dying will mostly benefit older people and so it is an issue with which gerontology should engage both in terms of research and service provision for the dying and bereaved.

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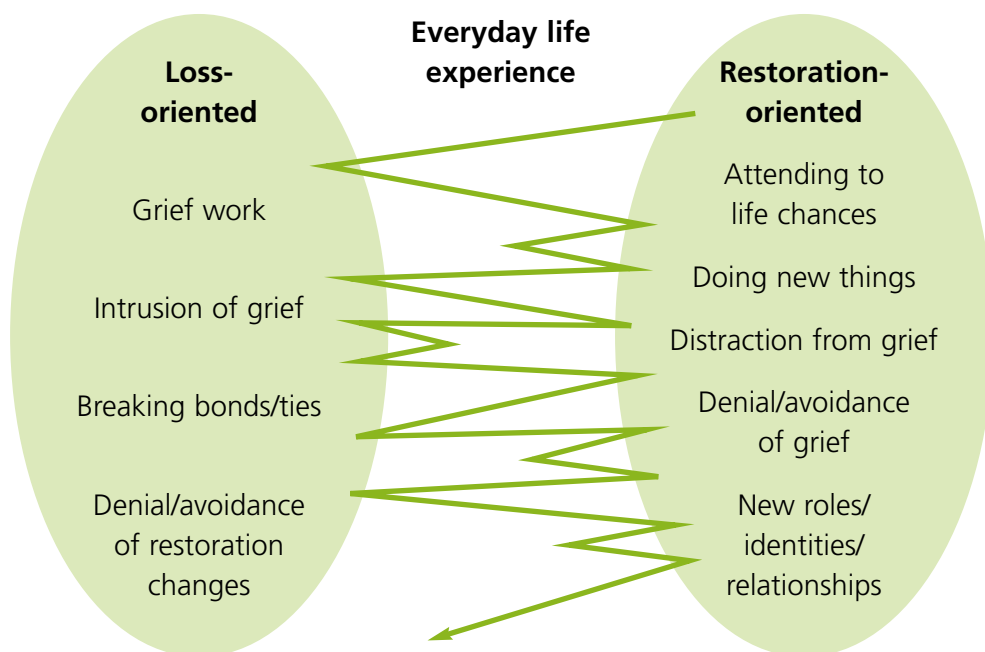
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Facilitator text 1.3 Alternative approaches

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 4, *Bereavement: Private Grief and Collective Responsibility*, which are reproduced by permission of The Open University.¹

Margaret Stroebe and Henk Schut have suggested an adaptation to the stages model of grief, which they believe sets up too rigid expectations of how people should grieve and can become prescriptive.² They have put forward a 'dual-process model' (see figure) which focuses on the coping process, and which they claim is more flexible and more sensitive to cultural differences.

A dual-process model of coping with loss.²



Stroebe and Schut argue that you cannot neatly package grief work into stages which need to be worked through before going on to the next stage. Their model encompasses both loss- and restoration-oriented coping. Examples of restoration-orientation include:³

- Mastering the tasks that the bereaved had undertaken (e.g. the finances or cooking)
- Dealing with arrangements for the reorganisation of life without the loved one (e.g. it may be necessary to sell one's house)
- The development of a new identity from 'spouse' to 'widow(er)' or from 'parent' to 'parent of a deceased child'

These restoration-oriented coping aspects of grief work are very much akin to the final stage of grief 'reorganisation and recovery'. But, Stroebe and Schut see the need for the bereaved person sometimes to be loss-oriented when they dwell on the lost loved person and focus on the pain of loss, and at other times to attend to life changes to do new things and be distracted

from their grief. They need to be able to 'oscillate' between the two, at times confronting, and at times avoiding their loss, and at times they need simply not to cope at all.

Although there is greater flexibility in this model and room to accommodate cultural difference, it is still a model of individual coping, with the expectation of coping as the norm and not coping as pathological. And the main focus of coping is on the emotions.

Tony Walter has questioned this emphasis on 'working through emotions' and proposed a new model of grief which links bereavement to biography.⁴ Walter starts from the premise that in Western societies by the end of the 20th century, the detachment from tradition, place, and kinship had created a lack of rootedness which means that people have to constantly recreate their own identity. In this context, Walter argues that the purpose of grief is 'the construction of a durable biography that enables the living to integrate the memory of the dead into their ongoing lives. The process of constructing this durable biography is through talk, as far as possible with others who also knew and cared about the dead person. So, the emphasis is much more on talk than on feelings. The main elements of Walter's new model of grief are contained in the following five points:

1. Many bereaved people want to talk to others who knew the dead person
2. Talking about or expressing feelings to a counsellor or in a self-help group may be helpful, but it may be a poor second best to those in point 1
3. The purpose of grief is not to move on without those who have died, but to find a secure place for them
4. For this place to be secure, the image of the dead normally has to be reasonably accurate, that is, shared by others and tested out against them
5. Unfortunately, these others may not be readily available in a mobile, secular and bureaucratic society which separates work from home, and disrupts tradition, ritual, and rootedness in place. Longevity compounds this

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Facilitator text 1.4 The effects of grief on physical and mental health

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 4, *Bereavement: Private Grief and Collective Responsibility*, which are reproduced by permission of The Open University.¹

There is a great deal of evidence linking various pathological states, whether psychological or physical, to bereavement. It is important to disentangle two strands in exploring the relationship of bereavement to pathology. The first sees certain types of grief as pathological in themselves, thus setting up two types of grief, one normal the other pathological. The second sees bereavement in terms of a causal connection to pathology where the pain and suffering of grief can lead to physical or mental ill-health. It is the evidence for the second assertion that we now review.

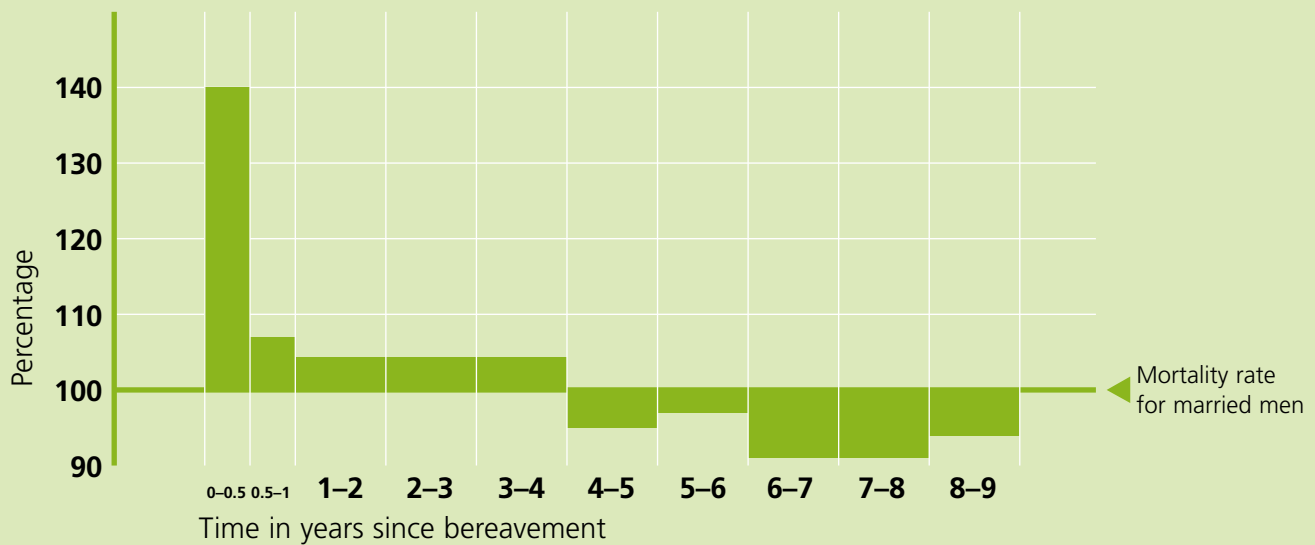
What evidence do we have that bereavement can cause ill-health?

Parkes' classic studies of bereavement provide us with an excellent review of the evidence of links between bereavement and mental and physical illness. He explores what he calls 'the broken heart' syndrome and asks whether people can actually die from grief.² Mortality data indicate that widows and widowers have higher mortality rates than people of the same age who are married, but these data are complicated because some widows and widowers remarry and it is suggested that the fittest are likely to remarry. Using data from his own work and from that of Young *et al*, Parkes shows that the mortality rate for widowers in the first 6 months after the death of their spouse was 40% higher than the expected rate for men of the same age who were married (see figure).^{2,3} The baseline of 100 represents what we would expect to be the death rate for married men over the age of 54. Anything above that line represents greater mortality for widowers, anything below that line indicates lower mortality rates. So it would seem that widowers are very vulnerable in the first 6 months after bereavement.

The evidence for widows is less convincing. In reviewing the evidence, Stroebe and Stroebe conclude that although there is some evidence of increased mortality after bereavement in widows, it is typically not nearly as excessive as it is in widowers.⁴

Parkes feels satisfied that bereavement in men is linked to deaths from diseases of the cardiovascular system, but is careful not to make direct causal links, preferring terms such as 'exacerbate' or 'precipitate'.² What we know of the body's reaction to shock – raised pulse and blood pressure, palpitations, sweating and acute anxiety – makes this a plausible theory. Parkes also makes claims for links between bereavement and mental illness and again amasses an impressive body of evidence from his own research and from many other sources. Stroebe and Stroebe also point out that

Mortality rate of widowers aged over 54 as a percentage of the rate for married men of the same age.²



perhaps most indicative of the devastating impact of bereavement are the findings for suicide.⁴ Widowers again are particularly at risk and in this case it is younger widowers who are more at risk. The risk of suicide is particularly great in the first few weeks of bereavement, and it is not only spouses but parents and sons who have elevated rates.

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Workshop 2 Grief in a care home for older people

Aim

To consider who grieves in care homes for older people.

Facilitator preparation

Before the workshop you will need to:

- Remind participants of the date, time, and place of the workshop, and ask them to bring their workbooks and a pen
- Study the facilitator guidelines and the following facilitator texts:
 - Facilitator text 2.1 (*What can you expect, my dear, at my age?*) – an article written by the manager of a care home for older people. This is an account of what happens when deaths occur in homes. It looks at the perspective of staff, relatives, and other residents
 - Facilitator text 2.2 (*Emotional labour of nurses*), which provides the context for the views expressed by the nurses on the CD
 - Facilitator text 2.3 (*The grief of staff*) – an exploration of how staff manage when residents die
- If necessary, make notes for the activities on the flipchart – keep them simple and clear
- Listen to CD tracks 1 and 2 and, on the day, make sure the CD player is ready to play these tracks
- Bring the agreed ground rules

Facilitator guidelines

Session 2.1 Introduction

5 minutes

Welcome participants. Direct them to p. 10 of the workbook and explain the aim of this workshop, which is to consider who grieves in care homes.

Direct participants again to p. 10 of the workbook and run through the programme and timetable for the workshop. Explain that, as in the previous workshops, they will be working in small groups, as well as taking part in discussions with the whole group.

Display the agreed ground rules.

Session 2.2 Discussion: who grieves in a care home?

10 minutes

Ask the group: who grieves in a care home? Encourage participants to share their own experience of the impact of a death on residents, relatives, and staff.

Discussion points

- Staff. Confine the discussion to establishing the fact that staff form attachments to residents and grieve when they die. Session 2.5 explores the potentially contentious issue of how far staff should openly express their grief
- Relatives. Relatives' grief is explored more fully in session 2.6, so try to draw on participants' experience within the home without addressing contentious issues at this stage
- Residents. Use your notes on facilitator text 2.1 (*What can you expect, my dear, at my age?*) to help you point out how easy it is to discount the losses of older people. Remind participants of the discussion about loss and grief in older people in workshop 1. There will be another opportunity to explore residents' grief in the next session

Teaching points

Recount the experience of the care-home manager described in facilitator text 2.1. Three deaths occurred in quick succession in the home and, in response to the general feeling of depression within the home, the manager engineered discussions with staff and residents about the deaths. It might be helpful to share with participants the feelings and comments expressed by the residents in the text:

- They felt empty and alone. They had got on well with the residents who had died, and their age did not minimise, in any way, their sense of loss
- Within a few days of the funerals, the rooms had been cleared of personal belongings, new residents had arrived, and by that time every trace of the dead resident had been expunged. Residents felt that it was as if the people had never existed
- Residents therefore reasoned that when they died, they would be forgotten with similar rapidity
- Residents had not discussed their feelings with staff because staff were busy and did not have time to spend discussing their sadness

Session 2.3 Small-group activity: hidden grief in a care home

15 minutes

Divide participants into two or three groups with a similar mix of levels of staff experience as the main group. In other words, do not place all the senior staff, for example, in one group.

Direct participants to p. 11 of the workbook (*Hidden grief in a care home*) and ask the groups to read the case study and answer the following question:

- How would you deal with the situation described?

Ask each group to make a note of two specific strategies to share with the main group, and to appoint a spokesperson to summarise the strategies for the rest of the group. Space is provided on p. 12 of the workbook for participants' notes.

Session 2.4 Feedback

10 minutes

Ask each group in turn to present their reactions to the case study and their two strategies for dealing with situations such as that described.

Feedback points

Although Emily had only known Rachel for 9 months, her loss was considerable and yet her need to grieve was not acknowledged. Moreover, she did not feel able to express her grief or share it with anyone else. Participants may suggest ways in which she could have been helped to talk about her grief.

Many care homes operate a policy to remove the bodies of dead residents as quickly and discreetly as possible to avoid upsetting other residents. However, participants may suggest a change to this policy to give residents a chance, if they wish, to view the bodies of their friends and to say goodbye. This option would have helped Emily.

They may also suggest that someone could have helped Emily to send some flowers (perhaps from the garden) to the funeral.

Rachel's death could also have been marked by an act of remembrance in the home. Such acts need not be morbid but could be used to celebrate a life. Emily might have liked to have organised the event, perhaps in the conservatory.

Session 2.5 Audio session: the grief of staff

30 minutes

Ask the group to listen to CD tracks 1 and 2. Track 1 records a group of nurses talking about how their training discouraged them from expressing their emotions. Track 2 records two care-home managers talking about their experience of staff grief in their homes. Facilitator texts 2.2 and 2.3 (*Emotional labour of nurses* and *The grief of staff*) provide background information.

After listening to the CD, ask participants to:

- Give their initial reactions
- Say how far staff can go in showing their emotions

If participants wish to make notes during this exercise, space is provided on p. 13 of the workbook.

Discussion points

Participants may have had similar experiences to those described on the CD. They may also have conflicting views about showing their emotions in the home. They may feel, as did some of the staff in the home described in facilitator text 2.1, that they are torn between being cheerful for the residents and overtly expressing their grief. Such feelings might lead to a discussion about the extent to which staff should become involved with residents. You do not have to resolve this issue, but do acknowledge that it is a tension and dilemma for staff. Certainly, becoming involved, forming attachments, and showing feelings are now not so likely to be discouraged in care homes as in the past. Indeed, this is thought to lead to a better experience for both staff and residents. Staff must, however, be supported adequately if they are not to experience burn out. Workshop 3 addresses the support needs of staff.

Session 2.6

15 minutes

Discussion: trigger statements 2

Direct participants to p. 14 of the workbook (*Statements about relatives' grief*) and ask the group to take a few minutes to tick the agree or disagree boxes and then to discuss each one in turn. Assure the group that, as before, there are no right or wrong answers to these statements; they are simply designed to provoke discussion.

Discussion points

Raise the following points, if necessary

Statement 1 ('You can tell which relatives will be most upset by the death'). Caution participants against making assumptions about which relatives will be most upset. Point out that the dynamics of the relationship between the relative and the resident might have been highly complex, and that the relationship goes back long before the resident arrived at the home. Also, the relative might be experiencing other major life events that make the loss of the resident seem even more upsetting or, conversely, less important.

Statement 2 ('It must be a relief now not to see her suffer'). Again, caution is needed. Although the end of suffering can bring relief, it does not minimise loss.

Statement 3 ('They didn't care when she was alive otherwise they wouldn't have put her into a home'). Remind participants of the many and varied reasons why people enter residential care. Their relatives may be old and frail themselves or they may have other commitments, such as children and grandchildren to consider. It is rarely an easy decision to take.

Statement 4 ('Once they're dead the relatives take over and you feel

excluded'). This might bring out feelings of resentment among staff who have, for example, been excluded from funeral arrangements for residents. Remind them of the similarities between this situation and that of Rachel in the earlier case study (p. 11 of the workbook). Explore ways in which they may might manage a situation in which staff feel excluded.

Session 2.7

5 minutes

Closing remarks

- Thank everyone for taking part in this workshop
- Point out that the workshops will help them build on their life skills and experience
- Agree the date, time, and place of workshop 3, and ask participants to write the information in the box provided on p. 15 of their workbooks. Remind them that it will address the support needs of the bereaved
- Finally, suggest that participants record their thoughts about the workshop and how it might change their practice in their workbooks (p. 15). For example, they might try to be more sensitive to the needs of other staff and relatives. Also, remind them to bring their workbooks to the next workshop

What can you expect, my dear, at my age?

The article below is reprinted by permission of Cruse Bereavement Care from *Bereavement Care* 1996;15(3):28–9. The author, Steve Scrutton was a manager of a care home for older people operated by Northampton Social Services Department. In the article Scrutton gives an account of what happens when deaths occur in care homes, and considers the perspective of staff, relatives, and other residents.

Introduction

Ageism, simply defined as the discounting of the needs and aspirations of older people, is inbred in our social attitudes. It is as rampant as sexism and racism, but much less discussed and understood. There is a tendency for all of us to believe that bereavement in older people is a natural concomitant to the ageing process, and something that does not require help. Such an acceptance of loss in old age has led to a neglect of the support and counselling required by older people and their carers in situations that would clearly warrant such assistance with younger people.

Discounting the losses of older people

As I write this from my office in a residential home for older people, I am conscious that outside are residents and day-care clients, their care staff, and visiting relatives and friends. Staff from my Home-Care Team are also visiting older people in their own homes. Surrounding us are the common features of old age – the process of gradual decline, ill-health, loss of function and mobility, and death. My staff are, of course, entirely used to dealing with this. It is part of their job.

The people we work with, a few in their 60s, some in their 70s, but most in their 80s and 90s, are resigned to the ageing process. After all, we all die and, as we grow older, there is an increasing acceptance of declining function and mobility, and the imminence of death. As the years pass, more of our friends and relatives, with whom we have shared our lives and experiences for many decades, die. But of course this is all quite normal – or is it?

Well, perhaps in part it is. But there is a crucial need to distinguish between the physiological and the psychological – the body and the mind. The longer I work with older people, the more important this distinction seems to me. The older we become, the more ill-health; disability, and death seem to be discounted. It is too easy to accept this process as an inevitable, naturally occurring part of life, and therefore as something that is somehow more acceptable than it is. We tend to forget the pervasiveness of loss in old age, not brought about by death alone, but through the loss of health, mobility, social role and status, and the ability to live independently. In making these

remarks, I am not seeking to criticise you – we are all to some degree guilty.

In a residential unit

Let us examine life within the residential part of this unit. Here, managers, social workers, and a variety of carers, kitchen and domestic staff are employed. Doctors, district nurses, and a variety of other health staff are regular callers. We ensure that residents are well fed and clothed, and live in warm, comfortable and hygienic surroundings. We seek to treat each resident as an individual with full rights, comply with their need for dignity, privacy and confidentiality, and ensure that they have as much choice and independence in their lives as possible.

We try (and generally succeed) in maintaining a happy and accepting atmosphere within the home. Yet inevitably loss is a regular visitor to the unit, and we have no counsellors, or even access to counselling provision.

Loss of independence

Some years ago, when I was new to work with older people, a member of staff who had been assaulted by a new resident came to talk to me (she had been kicked whilst toileting the resident). It became apparent that she was not aware of the indignity the lady felt at requiring assistance in this, the most private of all functions, and the grief and anger that such dependence caused her. We eventually agreed that we needed to counsel the lady about her loss of independence, to reach an agreement about her need for assistance in this and other matters of personal care, and what help she was prepared to accept.

The incident was instructive. The carer thought she was doing no more than fulfilling her caring task, for which she normally received appreciation rather than violence. The resident, on the other hand, was conscious of the indignity of requiring help, and lashed out in anger. How easy it is for such cross-communication to occur when we forget that people, regardless of age, maintain the same need for privacy and dignity, for understanding generally, as everyone else. The outcome was that we were able to maintain as much privacy and dignity for the resident as possible, whilst avoiding further violence to members of staff. Most important, we did not fall into the trap of seeing her as a bad-tempered, unreasonable, and ungrateful old woman.

Depression after three deaths

Until recently this unit did not formally recognise that there was a problem. Then, around Christmas, three popular, long-standing residents died in quick succession, including our centenarian. The atmospheres amongst both staff and residents became restrained. The weather was unceasingly miserable. We went through a period of high levels of staff and resident sickness. There was expression of sadness, but life within the unit had to continue. The

familiar routines could not stop. Everyone was busy. Soon, new residents replaced those who died. Everyone knew and accepted this. Yet the depression within the unit continued for many weeks.

Eventually, I engineered some discussions with key residents and staff – a series of bereavement meetings, and many interesting facts and feelings began to emerge. Several residents expressed their feelings vividly.

- They felt empty and alone. They had got on well with the dead residents, and their age did not minimise, in any way, their sense of loss
- Within a few days of the funerals, the rooms had been cleared of personal belongings, new residents had arrived, and by that time every trace of the dead residents were expunged. It was as if they had never existed within the unit
- They reasoned that when they died they would be forgotten with similar rapidity
- And, had they discussed their feelings with staff? Well, no. Staff were busy, and did not have time to spend discussing their sadness

Staff – the price of coping

I spoke to several members of staff too. One resident had died on Christmas Day evening, and carers had at one moment to care for the dying resident, then, in the next, move out to join the seasonal celebrations going on elsewhere. They felt cut in two. They welcomed the opportunity to talk about their feelings. Despite having cared for these residents, often for many years, no one had previously spent time with them discussing their feelings of loss. The routine work of clearing the vacant rooms to get them ready for a new resident, and continuing to look after the other residents, had to go on. Yet they had feelings about this, which they had never been able to express before. For them, as sensitive human beings, it was not routine. They were not automatons.

The personal price can be high. The husband of one experienced member of staff died. She seemed to cope very well during the early weeks and months, and soon returned to work. But then grief struck her, delayed and violent. She had dealt with the loss of her husband as she had learnt to deal with the loss of her residents. She had helped and supported everyone else, sons, daughters, relatives, and friends. Everyone had marvelled at how well she was coping. But now, she felt guilty at her failure to cry, her failure to recognise at the time the significance of her loss. Her way of coping with death was really no way at all. The price she paid for her learnt behaviour was high indeed.

Relatives and friends

You might expect that relatives and friends would have accepted that disability, ill-health, and death awaited the older people they loved? Not so! One daughter of a resident suffering from advanced dementia discussed her

mother's condition. This ageing, demented woman was her mother, yet not the mother she had known. That person had already gone, leaving someone who was hostile to her and who upset her. The daughter was doing her best and received only abuse from her mother. She confided that other members of her family had suffered dementia, and she feared that she might in time suffer the same fate. We discussed this briefly, and she said that it was the first time she had ever talked to anyone about it.

Ageism in older people

It is surely strange that within establishments such as this one, devised to meet the needs of older people, bereavement should be so neglected and it is surely sad that I, an experienced unit manager, should not have picked up these feelings before. Yet the situation I have described probably accurately reflects the low status of older people within our social structure. We should all be more aware, and take matters less for granted, when we consider our elders, and their needs.

Yet we also need to recognise another feature of ageism. Perhaps the most ageist group, those most likely to discount the needs and aspirations of older people are older people themselves. They do not complain. They say they have had their lives and that they are content with their lot, even when they are not: 'What can you expect, my dear, at my age?'

Too often, older people do not insist that they have a problem and it is important that their carers become as aware of what they are not admitting as what they are admitting. It is easier for them to complain of aches and pains than psychological distress. People of all ages are full of fears and self-doubt, and old age does not diminish these feelings. The experience of loss in old age is statistically more common, and we should indeed expect it, but we should never discount it. Each single statistic is a human experience which has to be borne, faced and dealt with as positively as possible.

Responding to the needs

We must also be careful not to underestimate the ability of old people to adapt to loss, however, devastating it might appear. The fact that they have become old people means that they have survived many personal losses, and done so successfully. They have, in many cases, proven their ability to survive the blows that life has dealt them. There is no reason to assume that these abilities decline with age. Certainly, the people who attended our meetings, low key events as they were, and talked about their feelings, felt better for having done so. In many ways, the meetings broke new ground. We now plan to start a picture gallery, a hall of fame, that will feature both current and former residents, thus ensuring that there is life after death within the home.

Emotional labour of nurses

The following article provides background information for the audio session and places the views of the nurses recorded on the CD in context. It is reprinted by permission of the author, Jocalyn Lawler.¹

Introduction

Much of what nurses' (women's) work entails, represents what Hochschild termed emotional labour – a commodification of feelings to suit the public (paid) arena.²

Emotions have largely been ignored by social science. Nurses are heavily involved in emotional labour because, as well as learning physically and procedurally how to wash another person in bed, there is an expectation that, as students, they will learn to control their emotions. Such emotional control is part of a nurse's 'professional' approach, that is learning how to perform body care and perform other nursing functions in a manner typical of the occupation.

Many aspects of nursing have changed since it embraced the concept of individualised patient care. One such change is the recognition that some emotions are normal, if not desirable, and that it is probably not healthy for nurses (or anyone else for that matter) to suppress some emotions. Historically, however, one characteristic of a 'good' nurse, was the ability to hide emotional reactions and to cultivate an air of detachment – a sort of professional distance from one's work. Many of the nurses I interviewed remember being expected to learn such emotional control and to learn it as they developed their nursing skills, and as they coped with a daily working life that was often difficult and disturbing.

One British nurse, in her 50s, described what she had been taught as a student nurse: 'I don't think we had very much at all on relating to people as individuals. You have to remember I'm British and the British stiff upper lip. I think it was just that it was not done. It was not done for the nurse to show emotion, it was to do with being professional and it upset the relatives. I think it had to do with being a professional person [and] we learnt it because I think if you showed any emotion you couldn't cope as a nurse – you weren't made of the right stuff (laughter). You weren't suitable if you showed emotion. We certainly didn't look sad, I mean, you were not allowed to look sad or grieve, but neither were you allowed to giggle around the place. You had to comport yourself – with dignity – no frivolity, not at all.'

With experience and more generalised social change, many nurses re-evaluate those early influences, particularly as they affect the ways in which they help patients come to terms with experience of illness and the lived body. The ability to control emotion is often used by experienced and expert nurses as one method to help patients through illness experience. It is also useful, however, to examine how the secondary socialisation of nursing and

the ethos of 'professionalism' as it was promoted in past decades affected nurses when they were attempting to overcome their primary socialisation as members of a 'civilised' society.

Other nurses, who are much younger than the British nurse whose experience is related above and who trained in Australia, relate similar experiences to those of their British colleague. The occupational ethos of emotional control remains relatively pervasive:

'You were never allowed to [show emotion], and you were never allowed to cry. You were only allowed to cry if the Charge Sister let you cry (laughter). You weren't allowed to cry if someone died or was really sick, you just felt that you had to give a little bit more to the patient, and you weren't allowed to laugh either if you could see the funny side of things. You had to appear what they termed professional which was very cold and caught up.'

'We weren't taught about emotions and you weren't taught that it's normal to feel disgust or things like that, which it is, isn't it? You know, you have a job to do and you do it, but no, not enough emotion or feeling was put into it.'

'[I was] always told not to get involved and become attached to the patient. It's hard not to get involved, I mean you do get involved. I think it gets passed down, you know when you're looking after a really sick patient [other nurses say to you] "you shouldn't get involved, you know" and so it goes on.'

R: No! No! No! It was never ever taught that you would feel unhappy or uncomfortable about a situation. It was never taught.

I: It was never what you could call a legitimate topic of conversation?

R: No. Never. Never. It was like tears.

I: Yes, you weren't allowed to have them.

R: No, there were many things that were taboo and that did not, therefore, require talking about. So, permission, so to speak, was never given to feel or [have] any emotional charge one way or the other. Feelings weren't allowed, there was no place for them really, so probably some feelings don't really emerge unless they are allowed to, you just find other ways of dealing with it.

Emotional control, as an ideal aspect of professional practice is now being seriously evaluated in the research literature. Benner and Wrubel, for example, claimed that it was impossible for nurses to care about what happened to patients and to help them during illness experience unless some degree of involvement occurred.³ Many of the nurses in my study would agree because they have recognised that emotional detachment does not work and that in some cases they have had to unlearn what had previously been taught to them: 'I don't know whether they [your teachers] expected it [emotional control] to help you through your training or your working years,

but it definitely didn't, and I find now that I'm trying to get back to the stage where – it's a hard process – you do think of them [patients] as people, and you don't classify them.'

'I think probably we were taught that [emotional control] to start, but I think I've learnt over the years that that isn't always appropriate to the occasion, that there are times when I think that as a person I have the right to let that other person know that they are embarrassing me or that I feel uncomfortable in a situation. I think that's improved. I think once upon a time you weren't expected to be emotional about anything. We weren't expected to feel emotion if a patient we cared about or cared for died. Now, I think it's quite acceptable for the staff to be just as emotional about the situation as the family is. I think that's good. I think it's important that we let the people we're caring about know that we really do care. You can't do that if you remain detached. Looking back I think that, in our early training, we were sort of expected to be a bit remote, you know [we were told] "don't be silly, nurse. Pull yourself together".'

'Oh God yes [I was taught to be detached]! Never sit on the bed! Don't do this! Don't talk to them [patients] That's a lot of bullshit.'

The structured style that characterises instruction in body-care procedures, and the occupational ethic of emotional control seem, on one level, to be a reflection of the British cultural traditions that are heavily embedded in much nursing ideology, and more widely in the culture. It is possible, for example, to trace direct links from contemporary nursing procedures to the early days of modern nursing in Britain in the mid-1800s. The procedural and ritualistic nature of such practices assists in the management of nurses' work because it allows the casting aside of normal social conventions about seeing people naked, undressing people, and touching the bodies of others. It also provides the nurse with a focus for concentration that excludes the social rules that are being broken.

Wolf argues that some nursing acts are conducted as rituals in order to make events socially manageable.⁴ Wolf's account, however, fails to consider the extent to which nurses choose not to follow standard procedures, nor how experience teaches them to ignore occupational practices that are impractical or dysfunctional in certain situations.

The notion of ritual, as the sole explanation for how nurses manage the body, is inadequate because it implies, at least in Wolf's terms, a form of social determinism that is not reflected in the accounts of nurses in this sample. Many of these accounts illustrate the extent to which, with experience, nurses modify what they have been taught and how they devise strategies specifically to deal with situations their instructors ignored. For example, they were not taught how to respond affectively in clinical practice other than to suppress whatever they felt, but lack of affect can be a very useful clinical tool.

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Facilitator text 2.3 The grief of staff

This is an adapted extract from a chapter by Katz on research carried out in care homes that explored the challenges managers face in coping with loss in care homes for older people and is reproduced by kind permission of The Open University.¹

It focuses on how, following the death of a resident, managers can ensure that the home continues to run smoothly and can put in place strategies for maintaining the equilibrium of surviving residents and support care staff in coping with loss. Much of the evidence for this chapter is based on two Department of Health funded research projects undertaken between 1995 and 2000.^{2,3}

Supporting staff

Managers endeavoured to minimise disruption of routines when a resident was dying or a death had occurred. As inferred before, their goal was to maintain the equilibrium of the home as surviving residents were seen to respond unfavourably to anxiety and rushing around of staff. Inevitably the presence of a dying resident increased pressure of work for care staff. Staffing levels rarely took into account the expectation that residents would need intensive caring and therefore all other jobs needed to be squeezed in order to create the space to care for a dying person. Popping in regularly to check on or turn a dying resident, negotiating with GPs, community nurses and relatives were all time-consuming tasks and placed additional pressure on what for most homes was an already stretched workforce.

Managers therefore grapple with the dilemma of ensuring that their staff can address the needs of all the residents at the same time as being supported practically and emotionally. They noted that at different points in the dying and death trajectory staff needed different types of support – this may entail reducing the workload to free a carer to provide one-on-one care to the dying person, or freeing up another member of staff to help with turning, bathing or administering pain control or to talk to distressed relatives.²

Two primary reasons were suggested for supporting staff around a bereavement.⁴

Firstly, to acknowledge the carers' loss, and secondly to enable them to continue with their other tasks. Three critical stages influence the functioning of carers following a resident's death. The first relates to how they find out about the death as this indicates the strength of the network within the home.

The second concerns the way in which managers directly support staff. The third explores the opportunity for staff to bid farewell to deceased residents and move on from their bereavement.

Informing staff about a death

Carers' experience of bereavement is influenced by the manner in which they discover that the resident has died. Most managers interviewed in Sidell *et al's* study said that carers were instructed not to notify their off-duty colleagues.² The reasons given for this related to cost of calling, time this would take away from work duties, and the imposition this would place on the private lives of carers. Despite this, it was apparent that this did not always reflect the reality of what happened or the wishes of the carers. Off-duty staff sometimes phoned in to enquire about an ailing resident. Some off-duty care workers were notified because they had requested this, or the manager believed that the particular carer was vulnerable or was seen to be especially close to the dying person or relatives.

Regardless of the manager's instructions, there was sometimes a spontaneous and unofficial chain which operated to notify other care workers. This reduced both the cost and the burden, and enabled close friends to inform and comfort each other.

'On the day it happens we divide the staff up and we ring, all of us that are on, we say well I'll tell so and so. We wouldn't want anybody to come in and find that that had happened. . .'

Indeed many carers told the researchers that they preferred to know if someone had died in order to prepare themselves before reporting for duty. Yet the majority of carers find out about a resident's death when they are next on duty through meeting a colleague, looking in the diary or at the notice board, at a meeting or, in the worst case scenario, finding a new resident in the bed of the deceased. Establishing the wishes of a carer in relation to being informed, in the same way as asking a relative, might be seen as good practice for managers.

Acknowledging carers' bereavement needs

Managers welcomed the opportunity to discuss their concerns about supporting themselves and their staff in relation to loss. Most did not feel sufficiently skilled in preparing staff for a death or addressing their emotional needs thereafter. Although about half the managers said they offered support to their staff, most felt inadequate in this role.

'I never feel they get that much support. They should but they don't. It is just time and we talk about it but you can't sit and listen. Time is so expensive and such a luxury. We find over the months, things come out which is probably not the way it should be at all, but we sit down at report (daily meeting to discuss residents).' (Manager home 24)

The reasons for their feelings of inadequacy related to the chronic state of understaffing which meant little opportunity for one-on-one support with a carer, and the burden of their other responsibilities following a death.

The most inexperienced carers needed particular attention: 'I find it's the

junior staff that usually get most distressed and usually they are comforted by a senior member of staff; they are usually asked if they would like to see the body as well, so if they are on duty in the morning, they would come in and we would go in with them if they wanted, but there is no support offered, it's literally the staff comforting each other.' (Manager home 15)

The importance of feeling and expressing emotions was noted by several managers: 'I always tell them that the day they don't cry is when they don't work here, because they have got to care or they wouldn't enjoy it . . .' (Manager home 23)

Managers thus set the tone regarding what is acceptable in terms of demonstration of emotions by carers.

In addition to having permission to demonstrate emotions, managers suggested that carers require opportunities to talk to their superiors and their peers about the deceased resident. Like surviving residents, carers need to rehearse the events surrounding the death. Some carers however find it difficult to talk about their feelings and this needs to be respected.

Carers themselves recognised that after their cry and their verbal post-mortem on the resident's death and their life in the home, they had to leave them behind and get on with the task at hand. This was particularly difficult after several deaths in succession when a tension emerged between having to maintain what carers saw as an appropriate demeanour, and feeling enabled to express their feelings and getting upset, even in front of relatives.

Good practice would therefore include managers endeavouring where possible to set up structured opportunities for bereaved carers to debrief more senior staff.

Saying goodbye to residents

Only a few homes encouraged staff on duty to bid farewell to deceased residents. Yet most homes sent representatives to residents' funerals; about 40% of home managers saw it as their duty to attend funerals themselves. Where geographically possible, home staff strove to go to funerals viewing this as the endpoint of their caring for that resident. Many carers went even when off duty, and were rarely financially compensated. As attending funerals appears to be so central to carers' jobs, managers should endeavour to facilitate this and, where possible, compensate them for going in their private time.

Conclusion

Managers of care homes for older people encounter residents' deaths frequently yet can find it difficult to support their own staff in their bereavement. Care homes become surrogate domestic environments for residents and consequently their carers experience grief when residents die. Managers therefore have the dual burden of coping with their own feelings

of loss and of frustration in not always being able to provide their staff with what they see as adequate support. Managers working in homes with good staffing levels, and where their job description includes ongoing professional development will have the best chance of feeling competent in managing loss.

References

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Workshop 3

Supporting bereaved people

Aim

To assess the support needs of residents, relatives and staff when someone dies in a home.

Facilitator preparation

Before the workshop you will need to:

- Remind participants of the date, time, and place of the workshop, and ask them to bring their workbooks and a pen
- Study the facilitator guidelines and the following facilitator texts:
 - Facilitator text 3.1 (*Supporting bereaved people*), which breaks down the concept of support into three different components and addresses helpful and unhelpful forms of support
 - Facilitator text 3.2 (*Supporting bereaved people through the mourning process*), which focuses on mourning, different mourning rituals, and funerals
- If necessary, make notes for the activities on the flipchart – keep them simple and clear
- Bring the agreed ground rules
- Prepare a celebration for the end of the workshop and for the signing of the certificates of attendance

Facilitator guidelines

Session 3.1

5 minutes

Introduction

Welcome participants.

Direct participants to p. 16 of the workbook and explain the aim of this workshop, which is to assess the support needs of residents, relatives, and staff when someone dies in a home.

Direct participants again to p. 16 of the workbook and run through the programme and timetable for the workshop. Explain that, as in the previous

workshops, they will be working in small groups, as well as taking part in discussions with the whole group.

Display the agreed ground rules.

Session 3.2

15 minutes

General information: categories of support

The notion of support is a much used but very loose term. It needs to be broken down into specific components if it is to be useful in helping bereaved people. In facilitator text 3.1 (*Supporting bereaved people*) support is broken down into three types: emotional support, informational support, and practical support.

Direct participants to p. 17 of the workbook (*Types of support*). Give the group a few minutes to read the overview, and then ask them to summarise the main points and draw out the specific points that would help relatives, staff, and other residents. You might suggest that they underline parts the the overview they consider important.

Teaching points

The following points are based on facilitator text 3.1.

Emotional support involves:

- Showing relatives, residents, and staff that you understand their feelings. You need to be available to listen and to allow them to express their grief, if they wish to do so
- Being prepared to absorb and share some of the emotion expressed by relatives, residents, and staff. This might involve touch, if appropriate
- Talking to relatives, residents, and staff about the deceased person, and encouraging them to share their memories

Informational support involves:

- Giving advice or information to relatives, such as information on claiming a death benefit, registering the death, or post-mortem procedures
- Giving information about the death to relatives, residents, and staff, if they were not present at the death. This requires careful communication and prior negotiation to determine if, for example, relatives want to be called at night, or staff members want to be notified when off duty, or close friends among the residents want to be informed immediately, even at night or at meal times

Practical support includes:

- Help for relatives with little support to organise the funeral or register the death
- Offering a meal in the home to relatives
- Enabling staff or other residents to attend the funeral, if appropriate and if they wish to do so

Many of these points can form the basis of guidelines for the home, which are the subject of the following activities.

Session 3.3

15 minutes

Discussion: guidelines for supporting relatives

Direct participants to p. 19 of the workbook (*Guidelines for supporting relatives*) and give them a few minutes to read the guidelines. The guidelines do not include arrangements for funerals or other types of memorials, which will be discussed in session 3.6. If participants wish to make notes during the discussion, space is provided underneath the guidelines.

Work through the guidelines and ask participants:

- Which guidelines are most important?
- Are the guidelines already part of policy in the home?
- What would prevent the guidelines from being followed?
- How would they overcome those constraints?
- Which of the guidelines would they like their home to adopt?

Discussion points

Remind participants at the beginning of the discussion that good communication, especially good listening, lies at the heart of all encounters with relatives.

Address the questions in turn and ask participants to give examples and suggestions. For example, it might be difficult for a small home to provide a room for relatives to stay overnight, as suggested in guideline 1.5, but a bed might be made up in an office or in a curtained-off corner of a sitting room. Summarise the points on the flipchart.

Session 3.4

15 minutes

Small-group activity: drawing up guidelines

Divide the group into two. Ask one group, based on the guidelines discussed in the last session, to draw up guidelines on how to support grieving staff. Ask the other to draw up guidelines on how to support residents affected by a death in the home. It might be helpful to suggest that some of the guidelines, such as guidelines 1.4, 2.1, 3.1, 3.2, and 3.3, might be adapted to both staff and residents. Encourage the groups to add their own guidelines, where appropriate. Remind each group to appoint a spokesperson to summarise the findings for the other participants. Space is provided on pages 22–23 of the workbook for participants' notes.

Session 3.5

20 minutes

Feedback

Ask each group in turn to present their guidelines. Discuss each set of guidelines and invite them to agree final guidelines that the whole group would like to recommend for the home. They can write the guidelines on

p. 24 of the workbook (first page of the guidelines section only at this stage. The second page will be completed in the next session).

In the next activity participants will have the opportunity to add some points about disposing of the body, funerals, and memorials. Therefore, by the end of this workshop, they will have three sets of guidelines to be adopted by the home, if the group wishes to put them forward.

Session 3.6

15 minutes

Discussion: respecting and remembering the dead

Ask participants to discuss the policy and practice in the home in relation to:

1. Disposal of the body
2. Attendance of residents and staff at funerals
3. Memorials
4. Respect for cultural diversity

Ask them if they would like to change the home's policy in these areas. Remind them of the confidentiality ground rule, in case they are reluctant to be critical.

Discussion points

Use your notes on facilitator text 3.2 to lead the discussion, the substance of which will depend on the practices used within the home.

1. Disposal of the body

Encourage participants to debate the pros and cons of disposing of the body discreetly. Refer back to the case study of Emily (p. 11 of the workbook), in which too much haste and secrecy prevented her from viewing the body and from saying goodbye. Emphasise the importance of giving people the choice to see the body, bearing in mind that some religions and cultures have specific requirements (see below).

2. Attendance of residents and staff at funerals

Encourage participants to say what they would like to happen and what prevents them attending funerals, such as distance, time, and feeling that they might be intruding.

3. Memorials

If participants do not already do so, they could create memorials, such as a book of remembrance or a memorial day when they remember people who have died in the previous year. Relatives could also be invited to take part.

4. Respect for cultural diversity

Refer participants to the chart on p. 28–29 of their workbooks (*Religious*

practices – a guide to general principles), and use it and your notes on facilitator text 3.2 in the discussion of this point.

Participants may or may not have a great deal of experience of different cultural practices. The chart provides a useful guide to some of the religious practices encountered in the UK. For simplicity's sake, the categories on the chart are very broad although some variations are noted. Many other variations occur but are too numerous to display. Stress that materials such as this are not a substitute for finding out what individuals need in relation to their mourning.

Guidelines

At the end of the discussion ask the participants to agree one or two guidelines in each of the four categories and add them to the guidelines that were produced in the previous activity. The guidelines will also need a title, such as *Respecting and remembering dead residents*. Space is provided for the guidelines on p. 25 of the workbook

Session 3.7

5 minutes

Closing remarks

At the end of this module, participants should have developed a set of guidelines for supporting staff, residents, and relatives, and for respecting and remembering dead residents. Discuss with them the possibility of presenting the guidelines to the manager with a view to adopting them as home policy. If successful, this would be a tangible outcome to the modules and would help participants put what they have learnt into practice. Participants might also like to photocopy the chart (p. 28–29 of the workbook) and display it in an appropriate place in the home.

Finally,

- Thank everyone for taking part in the workshop and congratulate participants on successfully completing this module
- Point out that the workshops will help them build on their life skills and experience
- Remind participants that they have a tangible outcome to their work in the form of the guidelines, which should help to improve the quality of care given to residents
- Suggest that participants record their thoughts about the workshop and how it might affect their practice in their workbooks, and that they should keep their workbooks for future modules (if this is not the last one)
- If you are running the modules in the order given, this will be the last workshop, so thank everyone for taking part in the whole programme and ask them for their thoughts on how it will affect their practice. If not, the next module will be either module 2 (*Communication*) or module 3 (*Pain and symptom management*). Agree the date, time, and place of the next workshop, and ask participants to write the information in the

box provided on p. 26 of their workbooks

- Encourage participants to take part in the other modules if they are not already planning to do so
- Mark the end of the module by signing each participant's certificate of attendance, or invite the manager to do so

Facilitator text 3.1

Supporting bereaved people

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 4, *Bereavement: Private Grief and Collective Responsibility*, which are reproduced by permission of The Open University.¹

Most of us are not naturally at ease in the presence of someone else's distress. How can we learn what to say and do? One important way is to learn from our own and others' experiences. In order to provide a context and structure in which to place individual experience, we will first look at studies which have tried to analyse the effects of social support on the experience of bereavement. Stylianos and Vachon maintain that: 'Social support is a transactional process requiring, for its optimal provision, a fit between the donor, the recipient, and the particular circumstances.'²

They identify three components to social support:

- Emotional support
- Informational support
- Practical support

Emotional support provides comfort and enhances the self-esteem of the recipient. Informational support means giving information, for example, about financial benefits that may be applicable. And, practical support is the giving of actual assistance, such as cooking meals or giving lifts.

The effectiveness of social support depends, as the quote above states, on a 'fit' between the giver and receiver, and the circumstances in which this exchange takes place. Stylianos and Vachon elicit various factors which they claim affect that 'goodness of fit'. Taking trouble to discover what would be the right amount of support is a prerequisite to the offering of appropriate support. Being over solicitous can be as irksome as a cooler approach. Cooking large meals may be unwarranted if the bereaved person has little appetite or alternatively finds cooking therapeutic.

The source of support seems to affect the acceptability of the support. Curiously it is not always those closest to the bereaved person whose support is most valued. Stylianos and Vachon draw on their own research and the work of others, mainly in relation to widows, to show that whilst family support is important in the immediate post-death period, the support of friends becomes as valuable if not more valuable than that of family. They also found that support in the form of information and advice was valued more when it came from a professional person.

Timing is another important factor in offering support that is likely to be perceived as helpful by people who are bereaved. Stylianos and Vachon suggest that emotional support may be best received in the early days after a bereavement but that some forms of practical support, such as introducing a widow to a new social group, may be more acceptable much later in her grief.

Funerals can provide a time schedule for judging the appropriate support to be offered. The post-funeral period is an indefinite time span during which the bereaved person will go on appreciating the support of others. But, key times when the bereaved may feel specially vulnerable and in need of social support are anniversaries such as the birthday of the dead person, their wedding anniversary if they were married, and the anniversary of the death. Commemorative messages can be very helpful at such times.

If we are to be responsive to bereaved people whose traditions are different from our own, then we need to know something of their customs and expectations of support. This is vital if there is to be a 'goodness of fit' between the givers and receivers of social support.

Those whose working lives are such that they are very likely to encounter bereaved people have to be especially well prepared, both personally and professionally, to be as careful as possible. For example, the police, ambulance service personnel, funeral directors, nurses, and medical and paramedical personnel working in various settings but particularly in general practice or accident and emergency, intensive care, oncology or continuing care departments of hospitals and care homes, will need empathy with and sensitivity to the immediate needs of bereaved people. A list of helpful and unhelpful forms of support appropriate to the care home setting is given below:

Helpful forms of support:

- Make yourself available, especially to listen and to allow them to express their grief to you if they wish to
- Talk about the lost person and share memories
- Offer practical help, in the immediate post-death time, with facing the necessary bureaucratic demands and later in making any changes which may be necessary
- Make a telephone call for a chat or to invite the person for a meal in the home in the weeks immediately after the death
- Send a 'sympathy' letter or card from the home
- Remember anniversaries and commemorate the dead person
- Acknowledge that the bereaved person may need support for a long time after the death of a loved one and invite them to visit the home for various functions

Unhelpful support – don't:

- Try to change the subject if the bereaved person talks about the dead person
- Avoid them because it is distressing for you to see someone who is clearly upset
- Say you know how they feel
- Try to point out that there are others worse off than they

- Tell them what they should feel or do
- Assume that because a certain time has elapsed that they will be feeling better

References

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Facilitator text 3.2

Supporting bereaved people through the mourning process

This text focuses on mourning, funerals in particular, and different mourning rituals. It is an extract from the book *Easeful death* by Katz and Sidell, which is reproduced by permission of the authors.¹

Funerals

Funerals provide an acceptable way of disposing of the body and in some cultures for aiding the transition into other states. They also act as a protection from experiencing grief too intensely by giving people something to get on with; the organisation of the funeral can in itself be therapeutic. Funerals are an important landmark in the mourning process; some people dread them, others find them comforting. Some people only come to realise the reality of their loss at the funeral, others are only able to start to heal when they have buried or cremated their loved one. But either way the funeral is likely to be a sensitive time for a bereaved person. They may be anxious about how they should behave, what to wear, how much overt grief they ought to display. Some people find it hard to display grief in public but fear condemnation if they seem to be unaffected. They may also be extremely sensitive to the behaviour of others. The numbers who attend the funeral can be significant, indicating the degree of respect paid to the dead person. Sometimes people attend who are not welcome, yet others who do not attend are sadly missed, leaving bereaved people feeling neglected or even resentful. The funeral can be experienced as a supportive occasion which will be remembered positively or a bleak and barren affair which leaves a scar for some time to come. Some people feel more comfortable with set rituals, others like the freedom to organise the funeral in their own way.

Mourning rituals are strongest where religion and cultural identity are important. As Britain has become a more secular society and local communities have become more fragmented, so too have mourning rituals declined. But for those who do practise a particular religion it is important that they are able to carry out the rituals associated with their religion. We need to review the mourning rituals of those who do practise a particular religion and the implications for providing social support. If professionals are to offer appropriate support then it is important to understand what is and is not acceptable.

Buddhists can either bury or cremate the body and a service is usually held in the house before going on to the cemetery or crematorium. At the service the emphasis will be on the impermanence of life. Mourning traditions vary according to the country of origin: some Buddhists will return to work within 3 or 4 days with no special restrictions on widows, whereas Vietnamese Buddhists mourn for up to 100 days, and women mourn their husbands or fathers for up to 3 years.

Muslims like to bury their dead within 24 hours of death. Only male members officiate at the burial, at which the body is buried in a deep grave facing Mecca. Muslims would prefer to bury their dead in a shroud without the coffin but there are restrictions on this in Britain. Some Muslims like to embalm the bodies and take them back to the country of origin. Friends and relatives are required to provide instrumental support to the mourners by feeding them for 3 days, which is the official mourning period; but mourning is finally ended after 40 days by readings from the Qur'an and a special meal.

Hindus and Sikhs always cremate. Both hold a short ceremony in the home before going to the crematorium. Sikh bodies are always dressed in their sacred symbols, the 5Ks. After the cremation mourners and friends return to the home. A period of mourning lasts around 10 days, during which relatives and friends visit and readings from the scriptures are given. There may be further rituals at 1, 3, and 6 months, and finally at 12 months to mark the end of the mourning period.

Like Islam, Judaism specifies burial, although some non-orthodox Jews choose cremation. Burial takes place in a Jewish cemetery and male mourners recite prayers and place the coffin in the grave. For the first week after a death, those who are obliged to mourn remain at home and pray three times a day. They are visited by relatives and friends. Mourning is concluded at the end of 30 days, except for children of the deceased who mourn for a year.

Christians either bury or cremate. For most Christians the funeral involves a church service sometimes with a mass or communion. The body is then taken to the crematorium or burial ground where further prayers are said over the coffin. Very little has survived of the mourning rituals which used to be common, such as wearing certain types of clothing; but some traditions are still observed in the north of England and in Ireland, where wakes are held which provide mourners with some emotional support from friends and relatives.

Mourning rituals remain strong in the Christian Caribbean community. Rees gave this account: 'The funerals of Afro-Caribbeans tend to be very warm-hearted occasions and they also last for quite a long time. When a West Indian dies, the death is treated as a community event in which everyone, including children, is involved. Neighbours support the bereaved family emotionally and by the provision of food. They attend the preceding wake and fill the church at the funeral service. Expressions of grief with lamentations and tears are much in evidence, but less obvious are the sashes close relatives many have wound around their waists to ease "the pain in the stomach" caused by the loss of their loved one. In spite of the grief, there is a strong sense of rejoicing based on the expectation that the deceased is going to heaven. The mood can be so joyous that a West Indian youth, speaking in a discussion group, said that he had never been so happy as he been at the funeral of his uncle. He felt particularly uplifted by the music and the singing of gospel songs.'

'Burial is the normal mode of disposal. Observances at the graveside are likely to show traces of former African customs; for instance, it is not uncommon for mourners to throw money on the coffin to help the dead on their way, and the grave is likely to be filled in before everyone leaves the cemetery to make sure that the spirits cannot escape. A second service is held 9 days after the interment to help the spirits find rest.'²

Those who do not belong to any organised religion have generally used the facilities of the state religion for such ceremonies as marriages and deaths. But many have found the performance of rituals which have little significance for them a most unsatisfactory way of marking the death of someone they love. Until quite recently it has been hard to organise a satisfactory funeral without resorting to the church. But the British Humanist Society has published a booklet, *Funerals without God*, which provides information and guidance on how to conduct a funeral, and there is a growing network of people who will conduct a non-religious funeral.³ The most important purposes of a humanist funeral are to remember the dead and pay tribute to the life that has ended; it is a summing up of the character and life of an individual. It is thus a celebration of that person's life. People pay tribute to the dead person, read appropriate pieces of literature and play favourite pieces of music. They are intensely personal affairs and so can be very moving occasions. It is becoming more common now for dying people to request certain features for their own funerals.

Professional carers may be asked whether children should attend the funeral. Much will depend on the age of the child, the relationship to the dead person and family traditions. Funerals can help children to acknowledge that a change has taken place and that other people share in the loss and value the dead person. But they do need information on what to expect and they should be given the choice to attend or not to attend.

The question of whether professional carers should attend funerals is a difficult one. Where cultural or religious traditions dictate who should and should not attend then it is important that these should be observed. There are often many practical reasons which make it impossible for professionals to attend funerals, yet they may have become very close to the dead person over a long period and would like to pay their respects. Even if they have the opportunity they may feel they would be intruding on a private and family occasion; but their presence can be very supportive to mourners, especially if they have been closely involved with the death. Hospices usually as a matter of policy try to send a key professional carer to a funeral. Sending flowers or messages of sympathy is almost always much appreciated by bereaved people.

After the funeral

The period after the funeral is often difficult for a bereaved person. Up to that time there will have been lots to do, and probably a lot of people expressing their condolences and support, emotional, cognitive and

instrumental. Then everyone else's life goes back to normal; yet for someone bereaved their life can be totally changed and they can feel very alone with their loss. This is a time when a follow-up visit or phone call from the hospital or hospice can be a lifeline. Knowing how or when to intervene and offer professional help to a bereaved person is difficult. But a visit or telephone call, especially if it is from someone who nursed or was involved with the dead person in some capacity, will usually be welcomed and it provides the opportunity to assess the situation. Most people will have adequate support networks and, however sad their loss, will not need professional help. But some people do not have very good support networks and there are some situations which may give cause for concern.

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Further reading

The process of death and the nature of relationships

This text is a chapter from *Death and dying in residential care* by Shemmings published in 1996.¹ The text is reprinted by permission of Ashgate Publishing.

One feature emerging from the analysis of the interviews was that when a resident declined slowly towards death acceptance seemed greater (although this may not necessarily be a predictor of the degree to which the person is mourned). Generally speaking, when this slow-motion death occurred those interviewed felt that it better prepared them for the death of a resident, and therefore they found acceptance easier. Also, the nature of the relationship appeared to influence significantly the level of acceptance, almost as much as the way in which the person died. Some interviewees experienced a confused set of emotions, between feelings of relief that the resident was no longer suffering, to feeling powerless that their role in the system prolonged suffering. And, for some, acceptance was impeded by a sense of guilt: they felt impotent to relieve the stress or pain in those they cared for, and experienced a sense of failure if a resident was removed to hospital to die.

Acceptance of the death of residents also seemed to be related to a principle of fairness: if someone is old, suffering, and has 'had their life', then it is more acceptable that they die. And yet there are subtleties within this conception. As already mentioned, if someone dies suddenly, without first having suffered an illness or slow deterioration, then acceptance of a resident's death may be more difficult for the worker. A sense of disbelief also seems to contribute to a non-acceptance of death. Feelings of uncertainty may follow, which can confuse staff further. As the psychoanalyst Langer pointed out: 'Man can adapt himself to anything his imagination can cope with; but he cannot deal with chaos'.²

Religious beliefs and the ability of staff to relieve suffering are influential factors, it seemed, in determining the degree of acceptance among those interviewed. For those with religious beliefs tensions and dilemmas abounded. In some cases, their experience with people who were dying caused them to question the existence of God, but often they concluded that it was the medical profession, and themselves, who were responsible for the prolonged suffering. For some, the notion that death came as a relief to the sufferer sometimes did little to promote feelings of acceptance.

For many of those interviewed, their acceptance of the death of residents was influenced by their personal experiences. Most of those who had someone close to them die, and whom they considered to have been too

young to die, seemed more accepting of the death of residents. However, it was apparent that some showed a dulling of affect [mood], leading to a diminished level of sensitivity, which it is possible to interpret as a defence mechanism. Whilst it is clear from the literature that many writers believe health workers need to develop defence mechanisms it is also argued that self-awareness and insight are important contributors to the delivery of appropriate physical and emotional care to dying people. Thus, if staff do not recognise the significance of personal experiences in their work they may become overwhelmed and suppress or ignore painful feelings. This is likely to affect both their work and their personal lives. Adjustment to the death of younger friends and relatives is seen as vital for all helping professionals, but perhaps this is especially true for residential workers. If they express or harbour resentments about caring for people who often say they wish to die, or who feel ready to die, it is likely to affect their ability to provide appropriate care.

Working within a residential setting engenders confusing and conflicting feelings for staff and this was apparent for most if not all of those interviewed: whilst they acknowledged death to be a natural event, and accepted the readiness for death of residents who were suffering, they felt unprepared for the emotional effects of caring intimately for people during their final months of life.

People who do not work in this environment rarely need to consider existential questions of death in such depth and with such frequency. Residential staff are attempting to marry the norms of society, which tend ideologically to accept or even welcome death at the end of a long and useful life, with their experience as workers, which requires them to accept death – and thus loss – among those to whom they have become attached during the course of their work. The act of balancing good and sensitive care for older dying people with the need to protect oneself from overwhelming feelings is not an easy task.

Forming attachments

Howe made three claims with respect to attachment:³

1. The kind of person or self we become forms and arises in social relationships
2. The type of self that forms depends largely on the quality of those social relationships
3. The way the self handles present social relationships, depends on experiences of past social relationships

In the main, most writers on attachment discuss it in relation to social relationships formed in the early years of life. Yet, in the present study many of the interviewees spoke at length about the way in which attachments formed with older people during the later stages of life were also of

importance.

There are a number of factors that contribute to the forming of relationships and attachments between residents and staff. On entering care many losses are experienced by older people; they lose their home and most of their personal belongings accumulated over many years; they may lose contact with friends, neighbours, carers, and home-care workers; even their family may not visit regularly after they enter residential care. Increasingly, admission is precipitated by a crisis and there is little time in which to plan the move into care. They may leave their home unexpectedly, never to return again. Often, therefore, they enter care in a highly vulnerable state and it is to staff who they will often turn to for comfort and a sense of security.

It is not only residents who are susceptible; staff too may have a need to form relationships or attachments with those for whom they care. However, there are dangers. The nature of the relationship between qualified professionals and their clients is a feature of the formal training of medical staff and social workers, and they are expected to explore fully the possible implications of becoming too attached. This is not generally the case within residential work.

Relatively few staff attend only the most basic of courses, which usually address the more practical aspects of care work. It was apparent from this study that there exists considerable confusion in the minds of staff about their role in the lives of those for whom they care: they know that they become attached (to greater or lesser degrees) to residents but invariably believe this to be wrong. Some said that their managers (and some trainers) had warned them of the dangers of becoming attached, and yet many face a dilemma because they believe it is an inevitable and vital part of their job to do so. From a psychoanalytic perspective, the potential is great for transference and counter-transference to take place between worker and resident; indeed a number of interviewees referred to residents as being substitutes for their own mother or father (who had died).

On the other hand, staff who did not experience or express feelings of attachment often said they were perceived as cold or unfeeling by their colleagues. Moreover, being upset about the death of a resident was seen by many as a weakness, and yet the same people often saw it as inevitable if they were doing the job properly, thereby producing another tension and dilemma for staff.

There is often a duality or reciprocity in the attachments formed in residential care. As mentioned, the emotional needs of staff too are part of the dynamic. It is often argued that if staff become appropriately emotionally attached it is possible that the care they provide will be of a higher standard, but the effects on the staff member when residents die might then be felt as strongly as if it had happened to a member of their own family. Also, repeated bereavements could incapacitate the worker to such an extent as to prevent them from working effectively.

If attachment is considered a good thing for the quality of care for residents at the end of their lives then the support mechanisms and training of staff will, it is argued, need to be at a similar level of intensity as that provided for health care workers in hospitals and hospices.

It is possible that those who do not form attachments with residents, perhaps appearing to favour a more distant approach, may be motivated to do so not because of a lack of sensitivity but as a form of defence against the inevitable feelings of loss when residents die. Interviewees often said that they felt unprepared for the task of caring for very frail, dependent residents, and they anticipated that support would be limited or not available at all. As a consequence, to help counter feelings of attachment it is possible that they tend to infantilise and patronise residents. Such reactions could be seen as a subconscious form of defence against powerful and painful feelings. The act of infantilising residents may make certain work, such as cleaning up faeces and dribble, more acceptable to the worker. Similarly, calling residents 'girls', 'pet', and 'dearie' may contribute to a process of de-sensitisation that helps workers distance themselves from the emotional effects of becoming attached whilst at the same time creating an illusion of intimacy.

Thus, it may serve to detach staff, ultimately from the death of residents. But the implications of such a pool of suppressed feelings could be considerable in terms of the well-being of staff and, in turn, of the care of residents.

Gender issues

The workforce of carers in homes for older people traditionally has been drawn from women, many of whom have family commitments that necessitate them being at home at key times of the day; often it is the opportunity for part-time and shift work which is particularly attractive to them. However, the level of unemployment has opened up this work to men, who in the past tended not to consider care work as an option. Male carers are forming a small but significant part of most staff groups in residential homes.

From the interviews it emerged that they soon came to appreciate that the occupation was quite unlike most others: residential work offered potential for making relationships and forming attachments with those for whom they cared, and from the interviews it was apparent that this was sometimes a shock or revelation to them.

Gender issues concerning the formation of attachment to residents also constitute another tension within practice. Although only three men were interviewed the implications of some of their experiences apply more generally to male carers in care homes.

Some of the men interviewed expressed surprise at their own feelings about particular residents (both male and female). They said that they had been unprepared for the nature of the work, not in the physical sense but in so far as they had not expected that they would become close to residents.

Although many of the women interviewed expressed their reluctance to show emotion when a resident died, most thought that if they had cried they would have gained the empathy and support of their colleagues. However, this was not the case with two of the male carers, who saw mourning as a selfish activity. Interestingly, however, another male care assistant claimed to have overcome some of the socially constructed expectations of male behaviour and said that he felt proud that he could express his feelings.

Although men joining the nursing profession is not new, the rise in the number of men entering the caring professions is uncharted territory. Thus, it is important to recognise any specific aspects about the male repertoire of characteristics within the care setting from the residents' point of view. Perhaps, for some older people, it will be important to help male staff to remain male, while still exploring ways for them to show their feelings towards residents as well as to discuss them with their colleagues. It is interesting to note that a number of authors conclude that boys appear to be more vulnerable to the effects of severed attachments than girls.^{4,5} If it were the case that men too are more vulnerable than women, then coupled with society's expectations that they should be brave and not cry, the implications for their emotional well-being as male carers could be profound.

The changing nature of the job

The nature of residential care for old people is changing rapidly. Dependency levels remain high, yet the staffing ratios to cope with high dependency generally are low. In addition, the rate of death in the homes studied was said to have risen over the past 2 years. The implications of this for the formation and nature of attachments between residential workers and residents are significant.

In the past, staff came to know about the biographies of residents through talking to them over many months or even years. Staff, too, shared stories about their own families: for example, they would take in photographs of weddings and christenings to show residents. Intimacies were exchanged, and they got to know what pleased individuals. It is conceivable that the increased physical care required now could lead to the creation of more rapid attachments between workers and residents; but it is also possible – and, it is argued here, probably more likely – that staff will be less willing or able to form attachments with people they know will die soon.

Finally, it will be remembered that all of those interviewed felt it was imperative that a dying person should not be left alone. However, with the increasing number of deaths in residential care the call on both the time and the emotions of staff may become untenable. Again, this knowledge may dilute the strength of attachment which care assistants are prepared to make with residents.

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