THE EXPERIENCE OF GRIEF: SOCIAL CONTEXT AND SOCIAL SUPPORT

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This paper is based on six case studies drawn from a larger project concerned with the ideas and experiences of 20 people one year after the death of a loved person. It describes and analyses their experience of the illness and death and their adjustment during the last year. The problems as they saw them and the sources of material and social support they received are described. The results are reported in the context of existing research and implications for bereavement care are discussed.

This article is based on a small study of the experiences of 20 people of the illness and death of a loved person (partner or parent) and their reactions to the loss as they saw these experiences after one year. It quotes the views of six people (three widows and one daughter, and two widowers) on financial needs and support during the illness and subsequently about the support they received from doctors, nurses and other staff during the illness and at the time of death. Respondents were also asked about formal and informal support they needed and received during bereavement. Their views are analysed with reference to theoretical and empirical studies, and the implications for support in bereavement are discussed.

Attempts to understand grief have focused on two outstanding features, depression and stress. Freud (1959) analysed grief and mourning in terms of withdrawing psychologically from the loved person and separating from them. He tended to take insufficient account of the social context and its influence on the process of bereavement. Bowlby (1979:1981) regarded grief as the disruption of the bond between the bereaved person and the lost attachment figure. His work is of help in understanding the function of social support for bereaved people. Both approaches have contributed to understanding the nature of grief, the process of mourning and the deterioration in health and well-being which are involved. The central concern of this article is to think of the importance of the social context in which people live and die and to interpret dying and bereavement as paradoxically isolating as well as social experiences.

Until recently it was rather rare to find social scientists acknowledging that their personal feelings are important positive ingredients in their research and writing. It is reassuring to find more open and candid comments about this now (for example Smith, 1989). It would be surprising to find anyone who feels easy about the study of loss and grief and who finds analysis of these experiences unproblematic. This preliminary statement is important because the planning and carrying out of this work was obviously influenced by the range of feelings it aroused in the people involved, including the writer. In a way this article may be seen as a personal attempt to ‘make sense’ of the fear of separation and loss as well as the hope that positive growth can emerge from these experiences.

A preliminary review of the literature together with discussions with staff and relatives at the hospice at which I worked were used to devise and pre-test the schedule of questions to form the basis of the interviews. The interviews were tape-recorded with the permission of the bereaved people who agreed to take part in the project. They were all very willing to take part and were asked to help in a letter
written by the researcher. Names and addresses were obtained from hospice records of deaths which had occurred one year or more than one year before the research interviews. The researcher simply worked back through the records until 20 people had agreed to take part. The interviews were recorded in their own homes with the exception of one man who was seen at the hospice.

Conversations with nursing and medical staff were helpful in providing additional information, but they were not tape-recorded because of the additional time that would have been needed to transcribe and analyse them.

A study made by Wilkes (1984) of the views of doctors, nurses and relatives contains information which could usefully be read in conjunction with the contents of this paper. Their views seem very typical of the groups represented.

The respondents

The views of four women (three widows and one daughter) and two men (both widowed), drawn from the main project sample of 20 survivors are typical of the views expressed by the majority of the people interviewed.

The names of the people who helped in the study (and the members of their families) have been changed and certain other personal information has been altered but the changes have been kept to a minimum so that the evidence presented is as clear and unvarnished as possible. The people whose views are quoted are now described.

Angela

Angela was 47 at the time of the interview, one year after the death of her husband Rod. He had died at the age of 52 in the hospice following an operation for stomach cancer. Angela said that she was only just beginning 'to feel normal' when we met.

Jane

Jane was 54 at the time of the interview and her husband Paul had died one year previously in the hospice after hospital treatment for a brain tumour. She was still feeling 'low much of the time'.

Pat

Pat was 50 at the time of the interview, her husband Alan having died at home one year before. He had been visited by the home support team and the doctor from the hospice. Pat said she felt depressed and inadequate and was 'bursting into floods of tears'.

Jack

Jack was 67 when the interview was recorded. His wife Betty had died at home 18 months previously. The family had been helped at home by the district nurse and the home support team.

John

John was 63 when the interview was recorded and he had retired from the RAF eight years previously. Be lived in a pleasant spacious city house with a large garden. His wife Meg had died of stomach cancer a
year before the interview.

Marianne

Marianne was 45 when the interview was recorded one year after her mother, Gill, had died in the hospice. The family had experienced a number of losses near Gill's death and the family structure was complicated. Gill had suffered from physical and psychiatric illnesses for some time. Her husband was admitted to a nursing home because of psychogeriatric illness during the time Gill was seriously ill. Gill's daughter and Marianne's stepsister, Mary, lost her husband a year before Gill died. Another daughter was involved in protracted divorce proceedings. Marianne had several problems in her own family: her older son was seriously ill and her daughter was unemployed. A younger son left home and lived rough for a time. Marianne had suffered from a depressive illness two years before Gill died. After Gill's death a bereavement visitor saw Mary regularly but no one saw Marianne.

Most people experience financial problems when a member of the family is ill and their income is reduced; sometimes hardship is due to help that could be available not being use. The ignorance of patients or clients is sometimes matched by the ignorance of health and advice workers.

The experience Jack and his daughter talked about in relation to the claim for Attendance Allowance is not uncommon:

Doctors vary greatly in their capacity to assess applicants sympathetically. When they were asked about the availability of financial support Jack said:

We missed out on social security. We were straight and honest. The Macmillan nurse had said did I know I could get the Attendance Allowance. She said Betty was entitled to get and she filled the form in and sent it off.

The younger daughter said:

I didn't like it. I did not like the doctor who came and examined Mum. It upset me. They talked in front of her. I did not like it. Obviously he could see she was ill. He did not have to do all that. Surely he could just have taken the Macmillan nurse's and doctor's word for it. I did not like her to be examined. And then at the end of the day we did not get it. We did not get a penny did we? I just wish none of it had ever happened.

Jack explained why he thought the Attendance Allowance was not paid:

I can tell you why. Because we were too honest. We could have had it from the October but Betty died before it was due - because of the six months waiting period. She died before she could get it. It really was not worth her having that examination. It was not worth any of it. He was pressing her tummy and she could not bear to be touched. Why do they do it? She could not do anything for herself for a long long while. So we slipped up really. We were straight with them about how we were looking after her but we got the dates wrong. We were looking after her for a long long time - longer than six months and we should have said so. She could not do any housework before we knew what was the matter with her. She was weak and very
ill. It was a long time. It seemed wrong to us.

I suspected that Jane and Pat rather understated the effects of worry about money. Although I asked about this early in the interview people were on the whole quite reluctant to talk about it at first.

Pat said:

When Alan came home (from hospital) he was really dependent on me. I was a teacher and I asked for leave. It was unpaid. Mile he was ill, I received nothing. When the Union fought for me and they paid me for one weeks compassionate leave, but the most of the time I got nothing. From having quite a good salary I went from that to nothing. Alan had been on sickness benefit after his strokes and then went on to invalidity benefit. The home support sister advised us about applying for benefits. I would not have known about any of them. The DHSS did not want to know when I went in to see them. They gave no information at all. They had no advice for me. They weren't any help at all.

Jane said:

We received invalidity allowance and we applied for mobility and attendance allowance, but we did not receive that until after he was admitted to the hospice. We could have done with more financial help but we managed with his pension and the invalidity benefit. We were all right. I'd be all right now if we'd stayed in the old house. But I really want to have an income. I'm on the employment training scheme and am going for job interviews.

Of the others interviewed Marianne and her family were not well off financially. She said that they managed'. John was the only person who had no financial problems. He had an adequate income -his pension from the RAF and his subsequent earnings and he had private health insurance.

Bereaved people who felt that the diagnosis of terminal illness could and should have been made earlier so that the patient's suffering could have been relieved, expressed anger against the doctors. When they talked about the patient's suffering they became very distressed. Relatives were also angry about the failure of doctors to tell them how near to death someone was or they were critical of doctors who told them clumsily or in an insensitive way. They found it very hard to accept the fallibility and defensiveness of doctors and one person felt very let down when her husbands doctor refused to see him.

Jack's elder daughter said:

At first they thought it was just that she was diabetic. We were thrilled to bits because we thought that was all it was. And then it didn't get any better. It wasn't until five months later that we found out what it really was.

John said:

The hospital had completely messed up the diagnosis. They could not detect the disease at an early stage. For years she had complained about stomach pains, especially if she had had a big meal. She went to see the doctor and they tried all sorts of different things and she was examined twice at the hospital. They found nothing. Talking
to other people this is a common fault that they don't find this particular cancer until it is too late... She was disbelieved. She was treated for depression at one stage. If people could be looked at more holistically it would help to avoid misdiagnosis.

Jane said:

Paul did not talk to me about his illness. I knew he was going to die but I did not realise it would be so quick. I did not have anyone to talk about it at home.

Angela too felt lonely, fearful and at a loss about how to look after her husband Rod when he came home after his operation for stomach cancer. She said:

I felt really lonely when Rod came home from hospital after the operation. That's when I needed someone. The doctor (GP) had phoned and suggested the hospice and Rod said: 'I'm not ready for anything like that!' The doctor had been most abrupt and said there was nothing more they could do. The surgeon at the hospital had told me that he had only a few months and I did not feel he was ready for anything like that. It was the way he was told. I think we needed someone then to help us with that news. I think I was trying to protect him. It was just out of the blue. He only had the children (both of us were married previously) but no one older.

When support was available during the final illness it was greatly appreciated as the following comment from Jack shows:

The support nurse was very good. She was good with Betty but she was also good with me. We also had the district nurse. We could talk to her as well. She was very good. Betty knew her all her life really and she was very nice. Me and Betty could talk to her. And the parson used to come to visit her from the church and every month she had Holy Communion. That helped Betty. But we could not fault the Macmillan nurse. We got very fond of her she was very kind. We did not like the idea of the hospice and Betty did not want to go in. She wanted to stay at home.

It had been found that not all patients and family members desire psycho-social intervention and some find it intrusive. With regard to bereavement intervention, it was noted in one study that when hospice staff were available for bereavement support through home visits 23 out of 28 survivors used the service. But there was an average of only two bereavement contacts which led to questioning of the effectiveness of the programme (de St Aubin and Lunt, 1986).

Of the people seen in the course of this study, only John said that he did not require any contact after Meg died. The others appreciated the contact they had had, but felt it was insufficient.

Jack said:

It was nice when the support nurse came after Betty died. It was nice to have somebody to come and talk who knew Betty. She'd gone through it with us. It would have been nice to have seen her more but we appreciated she was busy.

Pat said:
The home support nurse came to see me two or three times and the district nurse has too. Not recently but they came initially. I think it would help if the contact was continued not so much by a visit but by a phone call just to know that there is someone out there who cares. A phone call would have helped.

Jane said:

Since he died the only help I've really had has been from the family and I did go to the Thursday Group. But I missed several times and did not feel able to ask to go back. The district nurse we had was on holiday when he died and so I missed seeing her. At the practice they said 'The doctor will be round to see you are all right' but I haven't seen him. I've had no one really. I've been on this employment training so I've been out during the day and people don't come round in the evening. Yet the evening is the sort of time you can do with somebody.

After this Jane was silent for a long time and was quite tearful. Eventually she became more composed and talked about her employment training and future work prospects. Marianne said:

I've felt lonely. I would have liked someone to visit me like they did Mary. Someone outside the family. I haven't grieved properly because of all my other problems - just go from crisis to crisis. I think my son's illness has stopped me mourning. Everyone thinks I can cope but sometimes this last year I've been in a terrible state. I've been to the doctor twice. I unload to him - he has been helpful. If I'd had a visitor it could have helped.

It was clear that the formal support that was available was insufficient. It can be seen that several of the people interviewed were still very sad and distressed, but visiting had been discontinued after two or three visits up to six months after the death. The home support nurses comments were:

Oh, he always will cry. She meant so much to him. He'll always be like this.

Well we did see her once or twice but then she was out when we went. We haven't time to go again.

They know where we are if they want us.

It may be assumed that because an individual had returned to work that she did not need a support nurse to visit. If this was the case it was a dubious assumption to have made. Some of the bereaved people who were feeling very sad and anxious were very unlikely to initiate contact: they said this to the researcher. Jack, Pat and Jane said they did not want to take up the time of busy people. I'm not worth it. Befrienders or visitors would need to reach out to them and in some cases the researcher was able to introduce a voluntary visitor to them. The following quotations from Worden (1983) a leading writer on bereavement support this action:

...good grief counselling requires continuing support... counsellors can make themselves available to the survivor and family over the most critical periods at least for the first year following death the point I am making is that grieving takes time and the counsellor needs to see the intervention role as one that may of necessity
stretch over some time though the actual contacts may not be frequent.

In an examination of social and cultural differences in grief responses (Gorer, 1965) noted that family and friends can help individuals to recover from loss. Lopata (1979) said that grief, is more rapidly resolved in societies where there is family and community support on the basis off historical evidence from the USA - Comparing patterns of social support in Samoa with the USA Ablon (1971) also said that grief is more rapidly resolved in cultures where there is family or community support for the bereaved. Parkes and Weiss (1983) found that in cultures where the overt expression of grief is encouraged this helps to counteract delayed grief responses.

The people interviewed in this study all referred to the importance of family and friends (and whether or not they were available) at the time of the illness and death or during bereavement. Where other people were psychologically available some of the negative features of grieving were relieved if only to a small extent. Their comments about what social support meant to them amplify the results of other studies.

Jack lived in a small village near his two daughters who were with him during the research interviews. The village is a community in which relationships appear to be close and Jack's situation provides a contrast to those of the other people interviewed. They were town or city dwellers and sometimes were quite isolated, and not by their own choice. There were exceptions: John spoke of helpful neighbours, for example. Angela did not want social contact but valued the unobtrusive support she received from her neighbour. Sometimes family members lived a long way from the people who were bereaved and although there was contact by telephone this did not wholly compensate for face to face communication. Jack , described the direct way relatives were involved in caring for Betty.

He said:

Her sisters used to take turns to sit up with her at night. My daughters had babies and could not do that. They came in the day time. She had her family round her all the time. We all took turns. We started grieving before she died.

John had what he felt was strong support from neighbours living in the same city road. But in many respects his situation and his reactions provide a sharp contrast to Jack's. At the time of the research interviews Jack and his daughters were still very tearful and distressed and still talking of their loss. John seemed to have regained control more quickly and to have begun to reconstruct his social world and start a new close relationship.

John said:

I had some very very good friends across the road, who really looked after me after Meg died. My daughter was 35 when she died, married, no children, and she went home the following day. That's when you find out who your true friends are. But I had good support. In addition to the couple over the road there was a younger couple in their 30s and Meghad almost taken them as her children as our daughter was so far away.

Pat felt that she had to confront her anxieties and deal with her
loneliness at an early stage after Alan's death. She describes herself as an outgoing person and said she felt there was a lot of life ahead of her. She went away to a distant city for two days on her own, although she still felt 'battered' and in a state of shock, but she felt satisfied that she had been able to cope.

Pat said:

The family have been supportive - well my two sisters-in-law really. They are both widows. They are most helpful because they understand. One's husband had the same kind of illness as Alan, and the other died in rather a horrific accident. Friends? As a widow you are a race apart. You find out just who your friend are. Most of them seem to expect me to be able to cope. I could almost count on one hand the number of times our so-called friends have phoned to see how I am. One friend in particular has been very good. I've gone out and sought out people myself. from that sort anyway. I'm not going to sit within four walls and be inward looking.

Angela had rather a different experience. She said she was very withdrawn for six months after Rod died.

She said:

The first six months after Rod died I just could not cope with anything at all. I didn't want anybody here - I just wanted to be on my own in this house. Somehow it was the only place I felt safe. I couldn't do with people. I could not talk about him or anything. I just busied myself with the house, and my dogs and I just shut myself away from the world. I really feel I'm beginning to climb back out of the big black hole. My sister lives nearby. My daughter is only half an hour away and my son is in Yorkshire. I've been able to talk to all of them. They've all been brilliant. My neighbour is helpful too. We're not in and out, but she keeps an eye on me. I could go and have a little talk when I really felt down.

The experiences of six people of illness, and bereavement recalled a year after death have been described in terms of the resources available to them. Their accounts have been briefly set down against the background of some other empirical and theoretical work. It is assumed that such work should help in understanding the nature of grief and the deterioration some people experience after a loss. It should also help in developing methods of intervention to prevent or relieve pressure and some effects of stress. Some suggestions have already been made but the following points can be added in conclusion.

Two complementary aspects of grief, depression and stress have been studied to try to understand the range of sometimes contradictory or paradoxical physical and psychological reactions which people experience. These two aspects of grief were described by all of the people who helped in this project but the interviews were concerned particularly with their experiences of stress and how it was dealt with both by them and others around them.

There is now greater awareness of the pressures arising from financial and material problems described earlier. One result has been the considerable speeding up of consideration of claims by terminally ill people and payments to them by the Department of Social Security. Other attempts to change social policy in the
direction of greater sensitivity to the needs of patients and 
relatives, and particularly how they are dealt with, continue to be 
made.

Death and bereavement take place in a social context. It is therefore 
always important to study the influence of social and cultural 
factors on the process of mourning. In relatively recent times, 
mourning rituals in this country have changed remarkably. Formerly, 
the ways bereaved people should dress and behave with other people, 
and the length of time appropriate for the public expression of grief 
were clearly prescribed. Now there is a lack of established ritual 
and of a clear structure for mourners and Gorer (1965) suggested that 
this situation contributes to the difficulties people have in coping 
with loss. For example, in common with many bereaved people, it was 
assumed by her family and friends that Marianne was able to cope and 
that she could bear her grief alone.

It is usual for mourners to need time during which they are wholly 
pre-occupied with memories and thoughts about the person who has 
died. Marianne said it was difficult for her to have time to be on 
her own to look at photographs of her mother. She did not want to do 
this when members of the family were around and needed her. She said 
that the needs of others in the family, particularly a sister who was 
going through a difficult divorce and a son who was seriously ill, 
made it difficult for her to grieve. She said she had not been able 
to deal with her own mourning. Other people were competing for her 
attention and she felt she had failed by not mourning the loss of her 
mother and felt guilty about this, as well as her inability to 
comfort her sister and son as she wished. Marianne's experienced a 
complex set of cultural and family pressures which combine to 
postpone grieving and delay the process of mourning. Those supporting 
the bereaved person need to understand and find ways to facilitate 
the continuation of mourning when it has been interrupted, but 
Marianne felt she lacked support from family and friends.

As noted earlier, Lopata (1979) said that grief is more rapidly 
resolved in societies where there is family and community support. In 
some cultures (Japan, for example) the practice of ancestor worship 
enables the bereaved to keep a sense of the continued presence of the 
dead person in the family through their religion. Buddhists believe 
that the spirits of the dead can be called back to this world. Their 
mourning rituals encourage a continuing relationship with those who 
have died. The objective reality of loss is accepted and the 
disruption of the bereaved person's reality and identity is not so 
severe (Yamamoto et al., 1969). Thinking of the role of the 
bereavement visitor or from helping in the acceptance of loss and 
disengaging from the deceased requires that the meaning of 
relationships and a couple's shared reality should be considered. 
This is one reason it is suggested that it is helpful to encourage 
the widow to talk freely about the circumstances of her partner's 
death and about him as a person. By talking about their lives 
together, the bereaved will confirm that this was in the past. By 
paying close attention the visitor indicates interest in the topic 
and the legitimacy of talking about it. Some relatives and friends 
may not be so willing to listen repeatedly and may think it unhelpful 
to dwell on the past. By helping the bereaved to describe their lives 
before the loss, the distinction between this and the new and 
different situation which they now have to face if clarified.

This clarification involves the painful recognition of aloneness.
Grieving involves struggling with the role of survivor and can be seen as involving first denial and later acceptance of the reality of the loss. Once the role of widow is seen as unavoidable the process of reconstruction may begin. Although Marianne was able to talk to her general practitioner - she said she ‘could unload all her troubles to him’ - she was able to obtain assistance when she approached the social services department. They could not offer to help - perhaps because of high case loads and the absence of a statutory duty to help her - but did not refer Marianne to CRUSE or a similar body. Although offering a befriending service to the bereaved is a sensitive matter, Marianne’s experience is not at all uncommon. It is frequently found too that when formal support is available it is withdrawn too early for bereaved people despite evidence that it needs to be continued.

Of course, the loss of the relationship with the dead partner is not the only change which takes place after death and death is not the only form of loss. Many difficulties in adjusting to change follow bereavement. The availability and responsiveness of social support for bereaved people helps to reduce distress: professional services and professionally supported voluntary and self-help services are capable of reducing the risk of psychiatric and psychosomatic disorders related to bereavement. Bereavement reactions which are unusually intense or are inhibited or delayed are more likely to occur when certain risk factors are present. A painful or sudden death, a high degree of dependence on or an ambivalent relationship with the dead person and lack of family support are important.

The experiences of people described in this article indicate the importance of trying to understand the possible underlying meaning of behaviour and of mobilising informal support or voluntary help if this is acceptable and available. Helping people cope with loss and change has always been very much a part of social work. We all face the bereavement journey at some time but it does not have to be the isolating experience which so many people suffer.

References


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