

Bereavement: a protocol for primary care

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SUMMARY. Bereavement is experiencing a loss, particularly of a loved one, which leads to a natural cycle of grief that has recognized psychological stages. Even though bereavement does not fit the criteria for the biomedical model of disease, it is a medical problem as there is a resultant morbidity and increased mortality associated with the surviving intimates. A bereavement protocol, which could minimize the effects of bereavement, is proposed for organized care by the primary health care team in this neglected area for health promotion.

Keywords: bereavement; grief; bereavement counselling; protocols.

Introduction

BEREAVEMENT has been defined as 'being robbed of anything we value'.¹ It is a loss, particularly loss through death, but also the loss of, for example, a limb, partner, strength, health or independence. Grief can be defined as the psychological reactions to that loss and mourning is the particular form of grief which is experienced when the bereavement is the death of a personal intimate such as a spouse, family member or friend.² An understanding of these concepts is of singular importance to practising doctors if they are to offer patients and their families appropriate 'whole person' care.³

In the case of a terminal illness, it has been shown that the cycle of grief, for the patients and their intimates, can begin with the breaking of the bad news to them by a practitioner.⁴ Alternatively, it can begin when the intimates permit themselves to recognize that the death is imminent, or when the patient permits himself or herself to anticipate his or her own death,⁵ and thus the anticipatory grief process of the cycle is embarked upon.⁶ Converse to this process is the unexpected and devastating events involving sudden death, for example, the death of an apparently healthy baby from sudden infant death syndrome.^{7,8}

It has been said that 'there is no human experience so universal as grief after a bereavement. It is the aching sense of loss, the anger of unjustified hurt, the struggle to adapt to an unwanted newness of circumstances and the absence of relationship'.⁹ The trauma which the patient and those involved will experience can be summarized as a loss which affects the spirit, emotions and psychological make-up of a being and, in turn, physical health.

The increased incidence of illness following bereavement has been recognized since the time of Freud¹⁰ and 200 years ago grief was officially regarded by the registrar general as a cause of death.¹¹ In a survey of bereaved relatives, Wilkes found that one year after the death of an intimate almost half of the bereaved relatives thought their health was not good, 30% had been admitted to hospital and 12% suffered from major depression.¹² Additionally, research has shown that bereavement is associated with a seven-fold increase in mortality.¹³

Despite this evidence, bereavement remains neglected in health promotion activities. Yet, the opportunities for preventive medicine in this field are great¹⁴ and the family doctor needs to maintain a positive and effective role. One method of achieving this is through the implementation of a bereavement protocol.

Death and birth are fundamental events which are diametrically opposed in relation to the life cycle: birth is the providing of new life and hence a new member into the family, whereas bereavement is the taking away of life and the loss of a family member. An analogy can be drawn between them as the emotions experienced by the family intimates in both scenarios are of similar depth and intensity. It should also be recognized that grief plays an important part in the 'recovery' following a miscarriage or stillbirth.^{1,15}

'To die is as natural as to be born.'¹⁶

Death is no longer accepted as the natural conclusion to the life cycle as the ritual of death and mourning have been removed,¹⁰ with the subsequent oppression of grief. This and the institutionalization of death have resulted in limited exposure to it.¹⁷ Yet, people need to be given time and space to experience their grief surrounded by those they love, know and trust. This is where the family doctor is privileged to have the opportunity to assist via the existing doctor-patient relationship with the bereaved.

While the disposal of the corpse by cremation is quick and efficient, it reduces the opportunistic grieving process. Reminders of the deceased are discouraged within society as people now feel uncomfortable with them and instead those who are bereaved are advised to 'keep busy'. Although purposeful activity can be a therapeutic part of the healing process, it should not be used to compromise the gentle encouragement that is needed to support bereaved people in the exploration and expression of their grief.

Vulnerability of bereaved people

Following bereavement, people are at their most sensitive and vulnerable, yet a range of differing attitudes exist among professionals concerning bereavement. Many voice the hollow reassurance that, 'time will heal', but this can never completely be so. The hurt may wane with time, but the loss can never be replaced, only substituted with an acceptance of what has happened. If health care has been poor or inappropriate words have been used by a health professional this will remain etched in the minds of the mourners, thus slowing the healing process of grieving. It is the avoidance of this negative event that the implementation of a bereavement protocol aims to prevent.

It is important in our multicultural society for practitioners to be aware of the implications surrounding bereavement for individual ethnic groups.¹⁸ There are a number of critical issues which need to be acknowledged when dealing with patients from different cultural backgrounds.

Children also mourn and what is happening or what has happened must be explained to the child in a manner appropriate to the child's age.^{19,20} Behavioural changes should be anticipated but the resumption of a normal course of living is advised.²¹ It has also been stated that 'there is a possible association between parent death and mental illness, thus indicating that the provision of adequate parent replacement is a vital factor in the management of children where a parent has died'.²²

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Stages of bereavement

The anticipatory grief process accelerates as the expected time of death draws closer, whereas conventional grief, while carrying on indefinitely, is considered to diminish in degree as time passes.⁶

'Everyone can master a grief but he that has it.'²³

Reactions to death are variable, do not necessarily follow a set pattern and cannot always be resolved. There are, however, certain identifiable stages and points of time when events happen more frequently than others. If stages were to be isolated they might be shock, denial, anger, depression, resolution and acceptance.

It is thus difficult to define when the grieving pattern is no longer normal and pathological grief has begun. Two primary indicators of pathological grief are where a person delays acceptance or seems unaffected by what has happened. Precipitating factors in pathological grief, which predict a poor outcome from the grieving process, include low socioeconomic status, short terminal illness with little warning of impending death, multiple life crises and severe reactions to bereavement.^{11,22}

One of the most difficult problems that bereaved people have to face during these bereavement stages is that acquaintances often avoid them, because of a feeling of inadequacy in what to say. The result is isolation, thus compounding the psychosocial problems associated with the grieving process and it has been observed that this pain remains with the bereaved and that they inadvertently develop a behavioural disguise that they use in public.

There has been much research into the stages of bereavement.²⁴⁻³⁰

Bereavement protocol in primary care

The best primary support for bereaved people is 'to understand and be available'.³¹ In general practice, an ideal situation exists to help and support bereaved people and provide preventive care where problems are likely to occur. This should be a fundamental responsibility of the primary health care team.

A family doctor can hear about the death of a practice patient from many sources owing to the current lack of a national formal notification procedure.³² This information can be recorded and a programme of review organized for those who are bereaved. This programme should cover not just the time immediately after the death, but many months ahead. The following proposal is a formalization of this process.

Staff familiarization

Familiarizing practice staff with the protocol as well as familiarizing both undergraduate and postgraduate trainees in the practice is a necessity if the integrity and quality of the service to patients are to be maintained. A management audit can be conducted to ensure that quality is maintained and to identify any modifications which could be implemented to improve the service provided.

Information

A leaflet for patients containing explicit information concerning the necessary arrangements to be made at the time of death should be available within the practice for appropriate distribution. It should contain all local contact points, reflect the ethnicity of the location and be reviewed on a regular basis (North G, unpublished report, 1991). Similarly, a supply of leaflets con-

cerning related issues should be maintained for distribution at the practice, such as those produced by the Compassionate Friends. There should also be information regarding the local availability of children's³³⁻³⁶ and adults' literature³⁷⁻³⁹ relating to bereavement.

Practice death register

A practice register of all patient deaths should be maintained for both information and audit purposes. Each entry should contain details such as: name, address, date of death, cause of death and indications of where the information should be recorded in the notes of intimates. As there is no formal requirement for family doctors to be notified of a practice patient's death, the data for this register must be assembled from a range of sources such as hospital letters, community contacts and newspaper columns.³²

Case note entries

Recording the dates of birth, death and pertinent anniversaries relating to the dead patients in the notes of bereaved intimates alerts a consulting doctor to possible consequential effects of the bereavement. This is particularly important when practising within a large, multi-partner practice.

With this information the consulting doctor should be sensitive to unusual symptoms that occur at the anniversaries of death or other significant events. The first anniversary of the bereavement is a time when the patient may feel particularly low in spirits and may even present with inexplicable physical symptoms.

Additionally, notes for the deceased patient should be checked to ascertain if other medical records offices require notification. This should prevent any follow-up appointments being sent to the deceased, and thus avoid unnecessary distress.

Bereavement consultation

When a bereavement has occurred, a key worker should be allocated from the primary health care team (North G, unpublished report, 1991). Allocation ensures that the responsibility for bereaved people is shared equally among the team, facilitates continuity of care and also provides a focal care point for the bereaved person. The allocation should take into account the relationship which may already exist as bereavement support often begins before the patient dies, through care for the patient and his or her family.

Perhaps the first useful rule is not to delay the bereavement consultation. It should occur as soon after the patient has died as is practicable and this may even be at the time when death is certified. Secondly, care should be taken not to visit the bereaved person on the day of the funeral ceremony, unless attending in a personal capacity. Thirdly, during the visit the bereaved person should be given time to express himself or herself and the therapeutic periods of silence should be used for non-verbal communication to indicate empathy. The visit should largely be cathartic with the health professional spending most of the time listening, thus reflecting the following thought:

'I will not insult you by trying to tell you that one day you will forget. I know that you will not. But at least in time you will not remember as fiercely as you do now, and I pray that time may be soon.'⁴⁰

It is perhaps one of the most difficult consultations for the health professional and yet it is one which a bereaved person will remember with gratitude if the health professional is sensitive. The initial consultation is usually conducted as a home visit and is rarely interpreted as an intrusion on private grief, but often reinforces the view that the health professional is a caring individual who may be approached and trusted with problems and

future illness. To be effective, one has to have examined one's own feelings and fears about death and one's own responses to loss or possible loss. Our own sadness and despair and so our empathy will greatly enhance the care we can give to our patients.³ If personal contact with the bereaved person is not established then an appropriate, personalized letter can be delivered. An example of such a letter is given in Appendix 1.

Monitoring and review

A series of reviews is required to assist intimates with the progression through the recognized stages of grieving and thus preventing pathological grief arising through lack of follow up or appropriate referral. It is advisable to schedule a bereavement review as a home visit but surgery consultations can be used for opportunistic review if this is more appropriate.

The initiation of the review is integral to the bereavement consultation when the bereaved person can be asked if there is anything practical that can be done to help and it can be made clear that the doctor is available for follow up. For example, a bereaved person may like to attend at a later stage to discuss the cause of death and the terminology used in the death certificate.⁴¹ Following the initial review, those thought to require social support and specialized counselling should be closely monitored and introduced to the local contacts for bereavement support groups such as Cruse, Sands (Stillbirth and Neonatal Death Society) or Compassionate Friends.

Care and support can be provided by both simple befriending and organized counselling. These are not, however, the same thing, but both can be of benefit to bereaved people. Befriending is offering friendship, a listening ear and companionship. It is seldom seen as an intrusion, for bereaved people are often grateful for a listening ear. This type of psychosocial support can be made available in a structured manner through a network of trained volunteers offering an unselfish, motivated and sympathetic service.⁴²

Counselling comprises a structured programme identifying the physical, psychological, emotional and social needs of the bereaved person. Working through these needs in an organized manner is often referred to as 'grief resolution'. It requires the establishment of a working relationship built on trust in which patients are encouraged to express their feelings. This relationship alone should be of benefit. However, given the current climate where time is a constraint and there is minimal strategic provision made for counselling, an evaluation of a pilot scheme could be used to determine the actual benefit to patients.⁴³

Befriending and counselling should take place in the situation which is most appropriate to the circumstances. However, they are best done in the home environment where more associations with the person who has died can readily be made. They should be conducted, where practicable, by appropriately trained members of the primary health care team although many different people may be able to help, for example a neighbour, a counsellor or a clergyman. In New Zealand, undertakers or funeral directors continue to provide counselling and support for 12 months following the funeral as part of their contract with the bereaved person.

Ideally the counsellor should help bereaved people first to admit their loss and then to identify and vent their feelings.⁴⁴ It is important that they are given the opportunity to explore their feelings about life without their loved one, thus 'letting go'. Regular reassurance that their feelings are normal and that grieving is a normal reaction is vital. Finally, the most important thing is time, remembering that grieving often takes longer than the traditional year¹⁰ and this period is often regarded by the bereaved person as a 'limbo of meaningless activity' which has passed very quickly.⁴⁵

Conclusion

Bereavement is a healing process in which adjustments are made by intimates to their loss in an attempt to come to terms with it.⁴⁶ The death of a patient is not the end of care as bereavement care continues for those who grieve. As we are not able to 'calibrate suffering'⁴⁷ and thus identify grief in a quantifiable manner, it is important for professionals to avoid the commonly held, misconceived notions that people should 'pull themselves together' or that 'they will get over it'.

Bereavement care is a vital area which is often neglected in both health promotion and medical education. Support for those who grieve will enable the grief process to proceed smoothly, albeit painfully, and help to prevent pathological grief and psychiatric sequelae. This type of care is a therapy for restoring a person to renewed function, a changed person but nevertheless a survivor.⁴⁸

'Grief is itself a medicine.'⁴⁹

Appendix 1. Bereavement letter.

Dear

We were very sorry to hear that you have recently lost a loved one and would like to offer our sincere sympathy. This letter is to let you know that if the doctors or staff of this practice can be of any help to you during this very distressing time please do not hesitate to contact us.

When someone we love dies, particularly someone on whom we have depended, one of our strongest emotions is likely to be sheer panic, a feeling of helplessness and not knowing what to do. Unfortunately during this time of personal distress, decisions and arrangements have to be made. To help you through this time we have made available at our surgery a local information leaflet.

Any of the doctors are, of course, available to see you during surgery hours. If, however, you would like to discuss your situation in less rushed circumstances than normal, then please arrange an extended appointment during one of the sessions which we have set aside specially for this.

With our sincere condolences.

Yours sincerely

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