

Guidelines for bereavement care in Intensive Care units

GUIDELINES FOR BEREAVEMENT CARE IN INTENSIVE CARE UNITS

Report of the Working Group

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1. Summary of Recommendations

- All intensive care staff should have access to training in bereavement care and in communication skills. This training should begin during student courses. Training should continue as postgraduate courses accredited by an appropriate authority.
- Staff support programmes should be set up to allow staff to understand their own responses to loss and so deliver bereavement care more effectively.
- Information must be available to staff about cultural and religious rites around the time of death and information should be available to staff about local services and groups able to help bereaved families.
- Information must be available to relatives in all Intensive Care Units on what to do after a death and what help is available to them.
- Efforts must be made to ensure the privacy of grieving relatives and comfortable facilities should be provided for them.
- The patient's General Practitioner must be informed of the death. Consideration should be given to informing the relatives' General Practitioners.
- Facilities should be available to follow-up bereaved relatives.
- Each Intensive Care Unit must have a written policy for bereavement care with provision for audit and development of this care.
- A named member of staff should be responsible for training in bereavement care, for writing, auditing and developing the bereavement care policy, for the availability of information and for liaising with local groups offering related services.



2. Introduction

Most people have lost something or somebody important to them. Some of us will have experienced bereavement personally and most of us will eventually do so. Those working on an Intensive Care Unit (ICU) deal regularly with death and use their own experiences to comfort bereaved relatives. Most research on death and bereavement concerns patients with chronic or malignant disease; sudden death attracts less attention. Only a few studies have been performed in Accident and Emergency Departments (1,2) and ICUs (3). These concentrate on staff attitudes and facilities for bereaved relatives, rather than on the processes associated with bereavement.

In a study of 26 ICUs in the United Kingdom, the average intensive care mortality rate was 18% (range 11-31%) (4). This suggests that facilities are needed for significant numbers of relatives on every ICU in the country. At the moment, individual ICUs provide the best care they can for relatives of dying patients. However, generally speaking, this is done in isolation, without communication with other units. This results in a lack of support and cohesion in the care of bereaved relatives.

The motivation for these guidelines was a survey of the management of bereavement in ICUs in the United Kingdom (3). The replies indicated a widespread interest in improving facilities for the bereaved and feelings of inadequacy among staff dealing with the bereaved. The working party was set up to address these problems and produce guidelines. These guidelines have two aims:

- To raise awareness among medical, nursing staff and managers, of the need to provide care for bereaved relatives.
- To provide information and support to medical and nursing staff on individual ICUs so that they can provide effective care for the relatives of dying patients.

3. THEORETICAL BACKGROUND



i. The Moment of Death

Some background information on aspects of death and bereavement are useful in putting the recommendations for bereavement care into perspective and providing a resource to ICUs.

Although relatives may start to grieve before the patient dies, the moment of death marks their bereavement. Relatives need to know when the patient dies. However, there is a surprising diversity in the definition of death among staff. The concept of death has altered throughout the ages and is primarily a philosophical debate (5). Intensive care with its sophisticated technology for organ support has lead to a clarification of the concept of death.

In simple terms, death is the absence of life. An organism is alive if it is capable of functioning as a whole and interacting with its environment (6). This capacity for life is lost by different cells in the body at different times and reflects the process of dying. At some point in this process, the body irreversibly loses its ability to function as a whole and is unable to interact with its environment: this is taken as the time of death. Death is regarded as an event; dying is a process. This begs the question of the critical function or functions which have to be lost for the body to be declared dead.

In the United Kingdom, the approach to diagnosing death is outlined in the guidelines from the Conference of Medical Colleges and Their Faculties (7,8). This requires documentation of loss of critical brain stem functions, the thesis being that the brain cannot function as a whole without the brainstem. Death can, therefore, be diagnosed clinically if the patient has no heart beat, is not breathing and has dilated and unresponsive pupils because these changes predict or follow brain stem death. Fulfilling the more complex diagnostic criteria for brain stem death may be needed if the patient is receiving ventilatory support.

An important aspect of diagnosing death is to have a uniform concept of death in an ICU. This avoids diagnostic confusion among staff and mixed messages being picked up by relatives.



ii. Psychological Aspects of Bereavement

The sudden and unexpected loss of a family member is a stressful event that may lead to morbidity, or even mortality, in surviving family members. The care and sensitivity which the bereaved receive at this time will shape their memories of the bereavement. This may reduce the incidence of a "survivor morbidity", particularly amongst high risk groups who have poor social support networks. Properly trained staff are therefore well-positioned to start a healthy bereavement process.

It is important to recognise that caring and supporting families during the loss of a relative is stressful for all concerned. Although education and experience can be helpful, social and psychological support are vital. Providing this support for the families of a dying patient is a major but rewarding challenge for all professionals.

The Process of Loss

The feelings experienced by a bereaved or potentially bereaved family are more than sorrow at the loss of a loved family member. The response of the family will be dictated by previous experiences and relationships and will often include fear and anger as well as grief. No two families respond in the same way and individual members of the family can and do react differently. Each individual should be treated separately and generalisations and comparisons avoided.

Common behaviour patterns after bereavement include:

- An inability to concentrate and make decisions
- An inability to absorb information and use it effectively
- Panic
- Demanding or irrational behaviour
- Aggressive and abusive behaviour
- Withdrawal and passivity

Often the feelings and behaviour patterns are manifest before the patient actually dies as the relative anticipates the loss. Roberts (9) asserts that "Whilst the patient enters a unit in a state of physiological crisis, the family enters the ICU in a state of psychological crisis". The death of an individual results in changes in the family, not only because the person is dead but also because the loss of that particular relationship forces each individual to rethink the priorities in their life as well as consider their own mortality (10).

Stages of Bereavement

Lindemann first described the stages of bereavement in 1944 (11). Others (12,13,14,15) have expanded this idea. Essentially, the stages of the grief process can be described as initial shock and disbelief, followed by an awareness of the loss and its implications, often associated with feelings such as grief, anger or guilt. This stage evolves into a stage of resolution when the individual moves on. Although such stages are helpful in understanding the emotional state of the dying patient and their family, the concept of stages has problems. For example, it denies individual patterns of coping and integration and it assumes that the process of bereavement is universal and predictable for everyone in every situation.

One factor in the intensity of the grief experience is the relationship between the relative and the patient. Another is the preventability of the death (16). Thus, the death of a child may cause profound grief with feelings of loss of a future and of hope. On the other hand, death of an elderly parent also causes grief but with some expectation of that death and an appreciation of a long life.



A more obvious problem with viewing grief as a series of stages rather than a process is the assumption of hierarchy. People may not experience all the stages and there is considerable overlap between stages. Since individual patterns differ, family members are unlikely to follow the same bereavement schedule. The "stages" approach also suggests that grief should be over at a particular time (14). Time does not necessarily alter the emotional state of individuals. McClowry (10) reported that we needed a clarification of the various ways individuals and families handle grief. Once these patterns are known, interventions to support a family can be planned and evaluated.

Grief Responses

Lindemann (11) reported a number of psychological and physical reactions to grief:

- Somatic distress
- Preoccupation with the image of distress
- Guilt
- Irritability, anger and hostile reactions
- Loss of usual behaviour patterns
- Sighing
- Lack of strength, exhaustion
- Digestive upsets
- Altered senses
- Loss of warmth in other relationships
- Rapid speech, restlessness

Crying and yearning are frequent during the grief process, particularly in the acute phase: depression is usual during mourning (11). Bereavement, however, also has positive aspects. Characteristics of families coping with bereavement positively include:

- Ability to identify a stressor
- Ability to view the situation as a family problem rather than as an individual one
- Ability to adopt a solution-orientated approach to the problem
- Ability to show tolerance for other family members
- Clear expression of commitment to and affection for other family members
- Open and clear communication among family members
- Evidence of high family cohesion
- Evidence of considerable role flexibility



High Risk Groups

Some individuals are likely to suffer more intense grief responses to bereavement than others. In these individuals, both psychiatric and somatic morbidity and indeed, mortality, are increased. Subjectively, relatives may describe increased ill health or irritability and depression: objectively there may be increased sick leave from work. The incidence of psychiatric problems is higher than the incidence of somatic problems (18).

Factors which indicate a high risk of an intense bereavement reaction include:

- Unexpected loss - if the patient is less than 65 years of age, with no history of serious or chronic disease and no previous life threatening illness
- Sudden loss - the relative has had no preparation for the death
- The relative perceives their family as unsupportive
- The bereavement is perceived as traumatic
- The relationship between the deceased and the relative is perceived as ambivalent - often manifest as dependency, anger or guilt
- The relative has life crises other than bereavement e.g. financial

Individuals at high risk may benefit from counselling. Several services are available:

- Professional services by trained personnel
- Voluntary services with trained personnel
- Self help groups with or without help from trained personnel

The support offered by the different services varies in terms of time and intensity but the type of support offered is similar. Essentially, the aim is to ensure the relative understands that their process is normal and he has the opportunity to express their feelings and work through any previously unresolved losses. The counsellor in this situation becomes an important part of the relative's support network.

The results of studies on using counselling to reduce bereavement morbidity are difficult to interpret because of study design and unmatched control groups. However, it appears that for individuals at high risk, counselling significantly reduces morbidity. The effect of counselling is to reduce the risk in high risk individuals to that of low risk individuals without counselling. Professional input appears to be important but the type of help provided may be of secondary importance (19).

Care of the Family

When a patient's death is inevitable and care is replaced by comfort, the family need support and assistance from ICU staff. To ignore the needs of a dying person's family means care is incomplete. The comfort gained from proper care can enable the family to come to terms with their loss.

There are several needs of a relative anticipating loss (20,21):

- To be with the dying person
- To be helpful to the dying person



- To be assured the dying person is comfortable
- To be kept informed of the dying person's condition
- To know of the impending death
- To experience and express emotions
- To comfort and support family members
- To be accepted, supported and comforted by health care professionals.
- To be relieved of anxiety

Each individual will have some of these needs but not necessarily all. Individual needs should be met as they arise but not forced. For instance, a relative should be allowed to leave the dying person rather than stay if that is what they wish. Staff need to be flexible. In some situations, staff may need to give relatives space and privacy with the patient. In others, they may need to stay with the relatives while they are with the patient. Individual's needs are different and staff should be able to meet them whatever they are.

It is important to listen and to hear the concerns of both the patient (if sufficiently aware) and the family as well as accepting whatever feelings they express. The family should be included in discussions and should be informed of decisions regarding the patient's care. This allows the family to support each other through the process. It is important not to exclude children from the ICU, since they may imagine a situation far worse than reality. Children may also wish to be involved in discussions. Dealing with bereaved children and their parents on an ICU requires particular support from intensive care staff.

Every advance in medical technology produces new difficulties in decision making, particularly because resources are finite. The use of sophisticated technology and treatments on an ICU can lead to the technology becoming the focus of attention for staff, rather than the patient and family. From the point of view of the family, the sudden onset of a life threatening illness produces drastic changes in their lives. Their day to day existence becomes focused upon disease, its treatment, its course and its outcome. At such times, the stresses created by seeing a sick relative attached to tubes and highly technical machinery are accentuated by difficulties in communication between the patient, the family and the health care professionals.

iii. Cultural and Religious Aspects of Death

A defining characteristic of a culture is its attitude to death. While it is important to know the beliefs that underpin this cultural attitude, it is also important to remember that people are individual and have their own interpretation of these beliefs. If in doubt, it is sensible to ask. The predominant culture and religion of staff caring for patients in the United Kingdom is Christianity. This is a summary of important beliefs in other religions (22, 23). It is not exhaustive and further information can be obtained from local religious leaders.

Hinduism

Hindus believe that each person has a soul and that the ultimate goal is to free this soul to join the Supreme Being. A person's deeds in past lives determine his fortune in this life which in turn determines his future. Numerous gods are worshipped as personifications of a particular aspect of the Supreme Being but the three supreme gods are Brahma, the creator, Vishnu, the preserver and Shiva, the destroyer and regenerator of life. There are different sects within Hinduism with different beliefs and philosophies. Families worship at home and attend a temple for communal worship.

A Hindu believes in four stages of life. Brachmacharya, the period of education, Garhasthaya, the period of working, Vanapastha, the retreat from worldly ties and Pravrajya, awaiting freedom through death. Pravrajya should be gradual to allow the spirit to be released and to unite with the Supreme Being. A person near death is given water from the river Ganges and a priest may tie a thread around the wrist or neck: this thread should not be removed. After death, non-Hindus touching the body should wear gloves: the family may wish to wash the body themselves. The eldest son is responsible for the funeral arrangements and bodies are usually cremated as soon as possible. The ashes are scattered over water. Mourning continues for thirteen days after cremation, after which there is a special ceremony to mark the end of this period.

Sikhism

Sikhs believe in one God. The word Sikh means follower. Guru Nanak, the founder of the religion, is revered as a man chosen by God to reveal his message. The religion is based on the relationship of the individual with his God and on finding salvation by doing good. Sikhs believe in reincarnation as a path to perfection and union with God. The Sikh temple is under the care of a reader (Granthi) and has a strong sense of community.

When a person is close to death, the family, perhaps with the Granthi, pray at the bedside and read from the holy book. After death, the family may wish to wash the body but do not object to it being touched by non-Sikhs. In life and in death, all Sikhs wear the five signs of Sikhism: Kesh, the uncut hair; Kangha, a semicircular comb to fix the hair; Kara, a bangle worn on the right wrist; Kirpan, a symbolic dagger and Kaccha, underpants or long undershorts. Sikh men wear their turban after death. Sikhs are cremated as soon as possible and the ashes scattered over water. Mourning continues for about ten days during which women wear white. After ten days, there is a ceremony at the home.

Islam

Islam, the religion of Moslems, literally means "submission" (to God's will). Moslems believe in one God, Allah. They also believe that Mohammed, the founder of the religion, was God's prophet, the last in a line of prophets including Abraham, Moses and Jesus. The five religious duties of moslems are faith, prayer, almsgiving, fasting and pilgrimage to Mecca (the Hajj). The Koran contains the teachings of Mohammed, while the Sharia is a legal code based on the Koran and on the sayings and deeds of Mohammed. Moslems believe that death is God's will, that there is a life after death and that God will judge the person according to his deeds and send him to heaven or hell. Modesty is crucial to Moslems and nakedness is shocking to them. The mosque is in the charge of an Imam who is not required to attend the death or burial of a Moslem but may be invited.



The face of a dying person should be turned towards Mecca and the call to prayer is whispered in his ear by the family. After death, non-Moslems touching the body should wear gloves and the family may wish to wash the body themselves. The head may be turned to the right so that it can be buried facing Mecca. Moslems are buried, rather than cremated and burial should take place as soon as possible. Women do not attend the burial. Mourning continues for three days after the burial and the bereaved family visit the grave every Friday during the following 40 days.

Judaism

Abraham is regarded as the founder of Judaism. Jews believe in one God. The word of God is in the Torah which dictates the Jewish law. Jews also believe in an afterlife and the physical resurrection of the dead. However, these beliefs can have a wide range and Jews have a powerful grip on life in the here and now. This can produce an ambivalence to a dying person, although support of the bereaved is excellent. There are no last rites but the patient may wish to see a Rabbi.

Traditionally after death, a feather is left over the nose and mouth for eight minutes to confirm death. After this the eyes and mouth are closed, the arms put by the side of the body and the jaw bound. The body is then placed on the floor, covered with a sheet. The feet are nearest to the door and a candle is placed at the head. If it is the Sabbath (Friday sunset to Saturday sunset) the body cannot be moved. This is rarely practicable but the body should not be left alone until burial, which takes place as soon as possible. Orthodox Jews are buried after a ritual purification and are forbidden post mortems unless legally required. Less orthodox Jews may be cremated. Formal mourning is for seven days and support for the mourners is strong.

Buddhism

Buddhism acknowledges no God as creator but has many Gods, all less in stature than the Buddha himself. Buddhists believe in rebirth and that whatever a person does in this life influences the next stage in the process. They believe that if the teachings of Buddha are followed, they will come closer to Nirvana or a state of perfection. The four truths of Buddhism are: that suffering and human existence are linked; that suffering is caused by a human craving for pleasure; that sorrow can be abolished by destroying "unskilled states of mind" and that the eightfold path leads to the end of suffering. The eightfold path entails right understanding, aspiration, speech, action, livelihood, effort, thought and meditation. Freedom from suffering and sorrow is the state of Nirvana, which is a state of mind rather than a concept of heaven.

While Buddhists stress the importance of relief of suffering, they may be reluctant to take drugs which alter conscious level. This is because their state of mindfulness, important in meditation, is impaired. The Buddhist believes that both life and death are natural and they generally accept death. The body is usually cremated.



iv. Procedures after Death

After a death there are certain statutory duties which must be fulfilled. The aim is to provide accurate information on the causes of death in the population so that Public Health priorities can be established.

Certification of Death

The statutory responsibility of a doctor is to provide a cause of death “to the best of your knowledge and belief” (24). If the certifier has insufficient knowledge to complete the death certificate, the death must be referred to the Coroner or discussed with others who cared for the patient. Inaccurate certification of the cause of death is common (25) but measures to improve the information from death certificates are planned.

The quality of information obtained from the death certificate can be improved by:

- Avoiding abbreviations, question marks and vague terms
- Avoiding the terms “old age” or “senility” as a cause of death
- Avoiding a mode of dying such as “heart failure” as the only cause of death since this does not establish the cause of death

Accurate certification of the cause of death is important from a legal standpoint. In addition, it reduces the time to register the death and may reduce distress to the family. The certified cause of death should correspond to information given to the family during the patient’s admission. Any discrepancies should be communicated to the family, although in Coroners’ cases the results of the post mortem are confidential, until discussed in open court.

Registration of Death

The relatives of the deceased usually register the death after receipt of the death certificate. Under normal circumstances, this should be done within 5 days, although some cases may take longer. The relative must take the death certificate and the medical card of the deceased to register the death and, in return, they receive a disposal certificate which is given to the funeral director to allow burial or cremation. They also receive a form for the Department of Social Security and a certificate for insurance companies to allow pensions and claims to be processed.

Deaths Reportable to the Coroner

In certain circumstances, all people have a duty under common law, to report a death to the Coroner. In practise most cases are reported by doctors (60%) and the police (38%). The remaining 2% are referred by the Registrar of Deaths. Any death in England, Wales or Northern Ireland, where the medical practitioner cannot certify death as being due to natural causes must be reported to the Coroner. Coroners’ offices vary in their requirements for reporting deaths and in cases of doubt, a death should be discussed with the Coroners’ officers.

The main categories of reportable deaths are (26):

- There is an element of suspicion in the circumstances of death or a history of violence
- The death may be linked to an accident, no matter when it occurred
- The death may be linked to industrial disease or the deceased’s occupation
- The death is linked to an abortion



- The deceased was not seen by the certifying doctor either after death or within 14 days before death
- Any death during an operation or before recovery from anaesthesia
- Any death related to anaesthesia
- The death may be related to a medical procedure or treatment
- Where the actions of the deceased may have contributed in any way to their death
- Any death occurring in police or prison custody

There are a number of other circumstances where deaths are reportable to the Coroner for example, patients in receipt of some specialist pensions. There is also some variation in practice between Coroners. In some areas, deaths within 24 hours of hospital admission and deaths occurring while the patient was detained under the Mental Health Act are reportable to the Coroner.

The Coroner enquires into the cause of death if it is not known, or if it is unnatural. He has several courses of action. The Coroner may decide that a death is natural and that the doctor may sign the death certificate. He may ask a pathologist to perform a post mortem examination of the body. If this shows that death is due to natural causes, the pathologist may issue the death certificate and the Coroner will send a form to the Registrar to allow issue of the disposal certificate. If the death is not due to natural causes, the Coroner will hold an inquest. This is not a trial but is an inquiry to find out who has died and how, when and where they died so that the death can be registered. A jury is not usual but is called when the death occurred in police or prison custody or if death resulted from an accident at work. Requirements for inquests vary with local practice. Usually the death cannot be registered until the inquest is over but in some circumstances, the Coroner will issue an interim certificate to the fact of death to allow the estate to be cared for. The body can normally be buried or cremated after examination by a pathologist (27).

The Procurator Fiscal

The situation in Scotland differs slightly from that in the rest of the United Kingdom because the legal system is historically based on civil rather than on common law. The Procurator Fiscal in Scotland has a duty to investigate sudden, suspicious, unexplained or accidental deaths occurring in his district. Deaths which should be reported to the Procurator Fiscal are similar to those reported to the Coroner (28). The investigation the Procurator Fiscal makes into a death will initially be in private. A report on this enquiry is discussed with the family of the deceased and submitted to the Crown. After this, a decision is made as to whether or not a public enquiry is necessary to establish the cause of death. The public enquiry is called a "fatal accident" inquiry and has a jury. The main differences between the Procurator Fiscal and the Coroner are:

- The Procurator Fiscal is a lawyer appointed by the Crown: the Coroner may be either a lawyer or a doctor and is appointed by the local authority
- The jurisdiction of the Procurator Fiscal depends on the circumstances of the death and the district to which he is appointed: the jurisdiction of the Coroner depends on the presence of a body within his territory
- The initial enquiry by the Procurator Fiscal into a death is private: the Coroner's inquest is public

- The Procurator Fiscal collects evidence and leads the enquiry into the death but others help to evaluate the evidence: the Coroner also collects evidence and leads the enquiry but in addition, judges the evidence and issues a verdict or helps the jury to reach one

Notifiable Diseases

Certain infectious diseases require notification to the Public Health services to establish prevalence rates. The responsibility for notification rests with the medical practitioner attending the patient and should be made on clinical suspicion of disease without waiting for microbiological diagnosis. In practice, notification is often performed by microbiology departments but lists of notifiable diseases and notification forms are available from Infection Control Units. Acquired Immune Deficiency Syndrome is not a notifiable disease but doctors are invited to report cases in confidence to the Director, PHLS Communicable Disease Surveillance Centre, telephone: 0181 200 6868.



4. Recommendations



i. Training

Specific problem areas were identified in a survey of ICU facilities for bereavement (3). These areas were:

- Training in all aspects of bereavement care, particularly communication skills
- Staff support to enable effective care
- The availability of information for staff and bereaved relatives
- Facilities for bereaved relatives, particularly their need for time and privacy
- Provision for follow up of bereaved relatives

Training in bereavement care should aim to:

- Provide staff with the knowledge and information to deal with bereaved relatives
- Enhance the communication skills of staff so that they can communicate effectively with relatives around the time of a patient's death
- Allow staff to express their feelings safely and to develop an atmosphere where good bereavement care is regarded positively

Knowledge

A core of knowledge is essential to good bereavement care. Staff should know about the psychological aspects of the bereavement process as well as the practical procedures necessary around the time of death. Information is also important and should be readily available to support staff and relatives.

Information for Staff

The information needed by ICU staff is:

- Psychological aspects of bereavement
- Cultural and religious rites associated with dying
- Support mechanisms for relatives
- Administrative and legal requirements after death

This information can be presented in various ways. All ICUs should have a file which should be kept up to date. The file should contain the information above together with:

- Contact numbers of local religious leaders
- Contact numbers for interpreters of different languages
- Information on how a family can obtain emergency financial assistance
- Addresses for local accommodation



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- Local agencies available for support and counselling
 - Relevant papers on bereavement issues
 - A copy of the ICU bereavement policy

Information for Relatives

The information needed by bereaved families differs from the information for staff in emphasis rather than content. A booklet should be provided by each ICU that gives relevant information. There should be an explicit statement that the relatives should feel able to contact the ICU staff later on if they want help. The booklet should contain:

- An expression of sympathy
- Information on the process of bereavement
- Encouragement to express any feelings and emotions which follow loss
- The administrative procedures after death
- A list of local support groups and counselling services
- An invitation to return and information on follow up opportunities
- Encouragement to ask for any help or information not included in the leaflet

The booklet should have no cultural or religious bias. Information should be up to date and accurate. Maps showing where to go to collect certificates and register the death are helpful. These should include a description of how to get there, local transport routes and car parking facilities. Separate sheets can be prepared for the booklet for particular situations relevant to each ICU. These may include:

- Details in languages appropriate for local ethnic groups with a content taking into account their religious rites
- Particular details for childhood deaths
- Additional information on financial assistance
- Information for special situations such as deaths referred to the Coroner or deaths from illnesses where prophylactic antibiotics or other precautions may be necessary
- Other forms of presentation for the partially sighted, such as large print versions, Braille or audio tapes

Communication Skills

The distress of bereavement can be reduced by effective communication. An important aspect of communication is effective listening. Intensive care professionals need to be sensitive to non verbal signs of distress from the patient and their family. They should be willing to listen and to give information honestly, as well as to be aware of the effects of their



own non verbal signals to the patient and their family. Staff should also be aware of different meanings to verbal and non-verbal communications in different cultures and religions. Religious and cultural attitudes to death also vary widely and staff need to be aware of the issues involved. Interpreters should also have specific training in bereavement care.

Staff should also be prepared to ask about thoughts and feelings rather than assuming they know. An important method of support is to acknowledge the thoughts and feelings of each individual as real for them and to avoid trying to change or interpret these experiences. The involvement of all the family in important decisions such as withdrawal of treatment and organ donation allows them to take the role of advocate and in considering the patient's own wishes, to support each other, if necessary. Staff should also be prepared to talk to the children of the patient separately. Children may imagine situations worse than actually exist and a simple and honest explanation is often reassuring for them.

Often families have considerable contact with domestic staff, auxiliary nurses and other ancillary and paramedical staff. All staff should, therefore, have access to training in dealing with bereaved relatives. In addition, they should have access to training in particular situations, such as telephone communication skills.

Communication Procedures

As well as effective communication with bereaved relatives, an effective communication system must be present within the ICU. Ambiguous communications can be avoided by having clear policies on each ICU regarding disclosure of the patient's diagnosis and prognosis and making decisions about subsequent care. An effective way of recording interviews with the family in the patient's notes is essential to avoid conflicting information being given to relatives. The record should include those present and their reactions and apparent understanding of the situation. A system to record the relationships between various friends and family members of the patient may be useful and can be completed by the relatives themselves. Such a "family tree" could include the main supporters of family members. This information is usually known but not recorded.

The General Practitioner of the patient should be informed of the death. Staff should also consider communicating with the General Practitioner of a family member if they are thought to need help. Intensive care staff do not have a duty to care for a patient's relative: that is the responsibility of their General Practitioner. Problems may arise if care, such as night sedation or referral to other services, is provided without consultation with the General Practitioner. The patient and the relatives may have different General Practitioners who may not otherwise be aware of the bereavement. The General Practitioners of family members, who may require medical treatment, should be informed so that they can provide any necessary treatment. Other medical teams involved in the patient's care, possibly in other hospitals, should be informed of the death as soon as practical and copies of the discharge summary sent as soon as available.

A frequently overlooked area is informing other patients and their relatives of a death on the ICU. Other patients will notice the death of another patient and may become anxious. Patients' relatives often get to know each other well and they may hear of the death from other relatives. A discreet notice board for deaths may avoid embarrassing questions and demonstrate a positive attitude to death.



Teaching Techniques

Courses are available to train individuals in teaching communication skills. Such training is valuable since teaching techniques for communication skills are varied. For both undergraduates and postgraduates learning could involve:

- Role-playing (a new experience for most doctors)
- Observation (with trainees as silent witnesses)
- A bereavement care and communication skills module: part of ICU training for medical staff and nursing staff

Information about bereavement can also be presented at meetings and tutorials as part of orientation procedures for new staff and as part of an in-service training programme for existing staff. The courses should be professionally accredited by the relevant authorities.

Attitudes

Medical staff frequently regard their job as saving lives. Death may be seen as a failure. Medical staff on the ICU also do not have a duty of care for patient's relatives and may view their care as somebody else's responsibility. Nursing staff share this belief less frequently since they can continue to care for the patient and their family. The phrase "there is nothing more we can do" should not apply since much can be done after the inevitability of a patient's death is established. Starting a healthy bereavement process for the relatives is vital to their future psychological well being and care of a patient's relatives is an essential part of total patient care. The General Practitioner of relatives may not have sufficient knowledge about ICU to communicate effectively with the relatives and may not be available around the time of the patient's death.

ii. Staff Support

Medical training in Intensive Care Medicine is directed towards the patient and the relationship of the patient with the disease. Nursing training is more holistic and considers the patient's family relationships. Neither medical or nursing training involves how to care for the carer - ourselves. This usually means we fail to consider our own relationship with the patient and the family. This, in turn, can make it difficult for us to care effectively for either patients or colleagues.

Problems dealing with dying patients may be particularly acute when the patient is similar in age to ourselves, our children or our parents. The same problems may be experienced when caring for a dying patient with an illness similar to that of a relative or friend. Strength and courage do not replace sensitivity and honesty.

Supportive Environment

Dealing with the dying is regarded as one of the most stressful aspects of intensive care. If this stress is unresolved, the consequences for the individual are unhappiness and burnout. For the ICU, the consequences of occupational stress are low morale, high staff turnover, increased sickness rates, poor staff recruitment and a reduced quality of patient care. A supportive environment can reduce this stress but to do this must involve all members of the ICU team, not just clinical staff. A supportive environment is created by staff caring about each other, listening to each other's problems and offering support at all levels. Often this can be as simple as allowing staff who have cared for a dying patient for a time, to care for a recovering patient instead. At other times it may mean forming a support group.

Support Groups

Staff have individual coping strategies for managing stresses such as bereavement. Intensive care staff should have opportunities to discuss issues of death and dying together. These discussions may be informal, sometimes with a group forming only at times of stress. This often takes the form of a "Unit Night Out". Alternatively more formal arrangements may be made involving a facilitator.



As well as psychological needs, bereaved relatives have physical needs which require consideration. The facilities offered to bereaved relatives vary widely. The most important considerations are:

- How to provide time for the bereaved relatives
- How to provide privacy for them to express their feelings around the time of death
- How to provide the opportunity to return to the ICU for support, information or other issues

Time

Time needs to spent with the relatives after the patient has died. This is important both for the bereaved relatives and for the staff, who have usually had time to form an attachment with both the patient and their family. After a death, the family need time to express their feelings and to start to grieve. An important part of this is to say goodbye to the patient in whatever way they want. Many will wish to see the patient and some may wish to be involved in the laying out process.

The family should have a supportive individual from the ICU available to them at all times. The identity of this individual will vary with local arrangements. The creation of time to deal with relatives requires an increase in staffing levels. This, in turn means that the importance of effective early management of bereavement must be appreciated. The additional cost of extra staff, recruitment difficulties and the unpredictable need, may cause problems. These problems, however, need to be balanced against the costs of rapid staff turnover due to occupational stress and the morbidity of bereaved relatives. Often help is available in the form of Chaplains. Some ICUs have access to bereavement counsellors.

The nursing workload of caring for bereaved relatives should be an integral part of all nursing dependency scores. It should also be scored as part of the Therapeutic Index Scoring System (TISS) (29), acknowledging that care of the relatives continues after the patient's death.

Privacy

A frequent complaint is the lack of privacy for relatives. In particular, most ICUs lack a room separate from the ICU waiting room, which can be used for giving bad news to relatives. Often relatives are informed of an imminent death in the ICU office, and then ushered back into the ICU, or a general waiting room, when the need for privacy is greatest (3). A separate room would require careful siting and tasteful decoration. Intrusion can be stopped by use of a notice board or sign on the door. Other facilities which would improve the comfort of relatives and the bereaved, include:

- Nearby toilets, washing facilities, mirror etc, with facilities for children and the disabled
- Facilities for overnight stay
- A direct dial telephone
- A telephone directory
- Toys for young children
- Tea and coffee making facilities

Follow-Up

Bereaved relatives should be followed-up because:

- It provides an opportunity to answer any questions the family may have about the patient's illness and care
- It reinforces the support of the ICU for the relatives and gives an opportunity to acknowledge the family's grieving process
- It allows an assessment of the post-bereavement morbidity of the individuals concerned

If necessary and if available, counselling or other support may be arranged after liaison with the individual's general practitioner.

Bereaved relatives often return to the ICU for an informal visit, usually to see members of the nursing staff. Less frequently, they have a more formal appointment to see one of the medical staff. Which individual sees the relatives depends on the reason for their visit. The type of facilities for follow up which may be useful are:

- A book to record the names of relatives of deceased patients for those who did not care for the patient
- A named contact for bereaved relatives who could ensure visiting relatives meet staff known to them
- A letter sent to the relatives after a period of time inviting them to return
- An ad hoc arrangement where bereaved relatives see a consultant
- A follow up clinic specifically for bereaved relatives
- A follow up clinic for ICU survivors, extended, with sensitive timing of appointments, for bereaved relatives



Bereavement care is an important aspect of intensive care. It should be regarded as a quality issue by purchasers and providers alike. A programme for training staff in bereavement care should be in place in all ICUs in the country. This programme also needs development to remain effective, up to date and "fresh".

Responsibilities

A named member of staff should be responsible for organising and coordinating bereavement services for patients' relatives. This individual should liaise with local support groups and religious and cultural leaders so that appropriate information is available to staff and relatives. They should also be responsible for training in bereavement care, for writing and updating policies for bereavement care and for auditing these policies. This staff member should be appropriately trained and rewarded.

Staff support is the responsibility of all staff but a named individual should be responsible for setting up and maintaining programmes and liaising with any relevant agencies. This individual may be the same as the bereavement care coordinator or a different person, depending on workload and personality. They should have access to trained counsellors for individual needs or to facilitate staff support groups. The employer's responsibility to support staff should be outlined in a charter and adhered to.

Policies

Each ICU should have a written policy for the care of bereaved relatives. National policies, and even most Trust policies, are too generalised to be useful, although they may form a useful starting point. They tend to concentrate on the administrative details of bereavement and the legal aspects of death. Such policies need to be adapted before implementation by the ICU. The policy should include:

- A commitment to staff training in bereavement care and communication skills
- Outline of the training programme in place
- Outline of information available for staff and where this is kept
- Details of who to tell about a death and who is responsible for the communication
- Details of how to record communications with relatives, other staff and General Practitioners and who is responsible for recording this information
- Details of the information to be given to relatives including an invitation to return
- Information on opportunities for follow up
- A commitment to develop bereavement care, e.g. facilities for bereaved relatives
- A commitment to audit bereavement care
- Relevant related areas such as "do not resuscitate" orders, the diagnosis of brain stem death and organ donation
- Details of the staff support system in place
- The name of the individual(s) responsible for bereavement care and staff support on the ICU

Audit

A policy for bereavement care can only develop through feedback on its effectiveness. Audit of the policy by means of a checklist would ensure it was implemented. An example of a checklist is shown in Appendix 3.

Asking relatives their opinions of their care would allow assessment of the efficacy of the policy. In conjunction with this, staff should be surveyed on their response to training and staff support to assess the efficacy of these programmes. The staff members responsible for coordinating bereavement care and for running staff support programmes should also be responsible for auditing their area of responsibility.



5. Conclusion

In most ICU's, bereaved relatives form a large group. Their needs have been well described and should be met. At present, staff do what they can but there is a widespread perception that the facilities and support they offer their patients' families are deficient. Significant investment is necessary to allow ICU staff to meet the needs of bereaved relatives effectively. Moreover, the cost of not meeting these needs is considerable in terms of morbidity of relatives and stress to staff. Training will improve care but to deliver that care effectively, staff support is essential. The availability of information and improved facilities for relatives are also important. Each ICU should have a written policy for bereavement care with named staff members responsible for developing the entire bereavement programme. These improvements may reduce not only levels of stress amongst staff but also post-bereavement morbidity or mortality amongst patients' relatives.

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7. Appendix 1

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8. Appendix 2

Useful Addresses:

We have listed only some of the organisations that exist. A comprehensive list is available from the National Association of Bereavement Services. There may be many local support groups specific to your area that are able to help individuals. Contact numbers are usually available from the Citizen's Advice Bureaux. Most groups welcome input from health care professionals and recognise the difficult role of ICU's.

CRUSE: 126 Sheen Road, Richmond, Surrey TW9 1UR. Tel: 0181 940 4818

An organisation set up in 1959 which offers a wide range of support for all bereaved. CRUSE "national membership" is for those who do not have a nearby local branch. It offers help and advice on practical matters, a newsletter, contact addresses and a telephone counselling service. CRUSE "local branch" offers regular social meetings, counselling, and practical advice. CRUSE also offers a range of useful literature.

COMPASSIONATE FRIENDS: 53 North Street, Bristol BS3 1EN. Tel: 0117 953 9639

A nationwide organisation of bereaved parents offering friendship and understanding to other bereaved parents. Compassionate Friends has two sub-groups, one for parents who children have been murdered and the other for those whose children have committed suicide. For those working with the bereaved, journals, cassettes and videos are available on loan.

BRITISH ORGAN DONATION SOCIETY: Balsham, Cambridge. Tel: 01223 893636

A self help group for those whose relatives or friends have been organ donors. The British Organ Donation Society helps deal with and support people who may have issues arising from organ donation or the concept of brain stem death.

THE FOUNDATION FOR THE STUDY OF INFANT DEATHS: 35 Belgrave Square, London SE1X 8QB. Tel: 0171 235 0965 (weekday 09.00 - 17.00), 0171 235 1721 (evenings & weekends)

GAY BEREAVEMENT PROJECT: Unitarian Rooms, Hoop Lane, London NW11 8BS. Tel: 0181 455 8894

Individuals Who May Be Helpful:

The local General Practitioner, the local vicar, priest or other religious leaders. These people have experience in dealing with people in similar circumstances and may be able to link them with local organisations. If practical or legal advice is needed the Citizen's Advice Bureau is available.



9. Appendix 3

Example of a Checklist for Audit of Bereavement Care

Staff caring for patient trained in bereavement care COMMENTS:	YES/NO
Staff caring for patient trained in communication skills COMMENTS:	YES/NO
Training adequate for situation COMMENTS:	YES/NO
Opportunity used for training others in bereavement care COMMENTS:	YES/NO
Relatives told of death or impending death COMMENTS:	YES/NO
Accurate information given to other staff COMMENTS:	YES/NO
General Practitioner told of death COMMENTS:	YES/NO
Other medical teams told of death COMMENTS:	YES/NO
Communications recorded accurately COMMENTS:	YES/NO
Discharge summary sent to all concerned COMMENTS:	YES/NO
Other patients and their relatives informed of death COMMENTS:	YES/NO
Written and verbal information given to relatives in a suitable form COMMENTS:	YES/NO
Relatives given invitation to return for follow up COMMENTS:	YES/NO
Staff dealing with dying patient and their relatives had necessary support COMMENTS:	YES/NO
Relatives opinion of care sought COMMENTS:	YES/NO

