

including physical, cognitive, social and emotional, to show how each influences the other. Try to use what you have learnt about other periods of development to inform your thinking here. For example, it is generally accepted that cognitive skills are socially situated and experience helps determine a child's ability to perform certain tasks. Why, therefore, should development progress any differently in adulthood? Making these links and applying the principles learnt elsewhere shows synthesis of knowledge and will make your answer stand out.

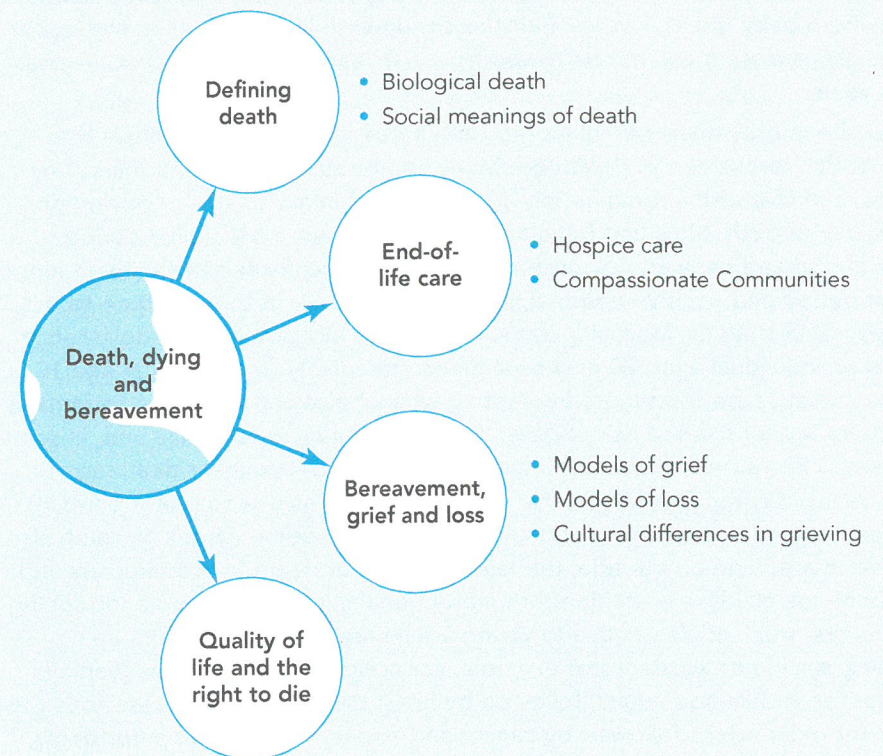
Explore the accompanying website at www.pearsoned.co.uk/psychologyexpress

- Prepare more effectively for exams and assignments using the answer guidelines for questions from this chapter.
- Test your knowledge using multiple choice questions and flashcards.
- Improve your essay skills by exploring the You be the marker exercises.

Notes

11

Death, dying and bereavement



A printable version of this topic map is available from
www.pearsoned.co.uk/psychologyexpress

Introduction

The final stage of the lifespan is death. As famously noted by Benjamin Franklin, death is one of life's certainties. However, there is much confusion in our society about when life begins and when it ends: on the one hand proponents and opponents of abortion argue about when life actually begins; on the other there are arguments about whether a person in an irreversible coma is truly alive or whether a terminally ill patient in agonising pain should be kept alive or allowed to die naturally.

Death can come at any time in the lifecycle, although we tend to believe that death in old age is the most natural. While life expectancy has increased over time, the greatest increase is in survival at birth. Life expectancy at birth in the UK has reached its highest level on record for both males and females (ONS, 2010). Life expectancy for a newborn baby boy is currently 77.7 years and for a newborn baby girl 81.9 years. Females continue to live longer than males, but the gap is closing and has narrowed from 6.0 years to 4.2 years over the past 27 years.

Despite improvements in infant mortality rates, the first year of life is the most dangerous one in childhood. Many infants still die during the first few weeks of life, with approximately 40 per cent of infant deaths occurring on the day of birth. Male and female mortality rates are most similar during childhood and early adolescence. Most children are at their healthiest during this period and positive parental influences are thought to contribute to this favourable statistic. Mortality statistics begin to increase in late adolescence and an individual aged 20 may be 4 times more likely to die than at age 10. The statistics are even more interesting when males are compared to females – there is an increased risk of death for males during these years and, in some cases, a 23-year-old male may have the same risk of imminent death as a 35-year-old male. The reasons for this include deaths due to motor accidents, misadventure due to risk-taking and suicide. The leading causes of death also differ depending on our age: the leading cause of death in preschoolers and school-age children is accident or unintentional injury (for example, poisoning, falls, fire, etc.); adolescents and young adults are more at risk from being killed, suicide or accident (for example, car accident); cancer is the leading killer for middle-age adults, followed by heart disease; heart disease tops the list for older adults followed by cancer and stroke. Perhaps not surprisingly, individuals also report very different feelings about death depending on their age group. Likewise, how we experience the loss of someone close to us also differs depending on our age and developmental stage.

→ Revision checklist

Essential points to revise are:

- Biological and social definitions of death
- Factors that impact on feelings of grief and loss
- Models of end-of-life care
- Ethical issues concerning quality of life and the right to die

Assessment advice

- As with prenatal development and birth, it is easy to see death and dying as very biological processes. However, you are studying psychology, not medicine, and it is therefore important to focus your answer on the wider issues related to bereavement and loss.
- As psychologists we are interested in the biological definition of death, but primarily because of the social impact that such definitions will have. It is important to remember that the social meaning people attach to death is more important to psychologists than biological definitions since these emotional beliefs will impact on how people negotiate bereavement and loss.
- Whatever kind of assessment you do, try to remember there will many factors that affect how someone copes with death and dying. The obvious one from a developmental perspective is age and developmental level. Thus our understanding of death is affected by cognitive abilities. However, as a good student you will know by now, nothing is that simple. How might experiences, social contexts and cultural norms also affect how death impacts on us? As with other areas you have studied, remember to take a critical approach and to take all aspects of development into consideration from cognitive through to social.
- Finally, remember that although death is the end of the lifespan for each and every one of us, death affects not only the dying but also those left behind. What are the impacts on development for individuals who experience death of a loved one? Is there a critical age at which loss might impact on developmental processes or are individual factors such as social support more important? Good assessment answers will try to take account of many factors and make links between the different areas of psychology.

Sample question

Could you answer this question? Overleaf is a typical essay question that could arise on this topic.

* **Sample question***Essay*

Evaluate the importance of social, cultural and developmental influences on our beliefs about death, dying and bereavement.

Guidelines on answering this question are included at the end of this chapter, whilst further guidance on tackling other exam questions can be found on the companion website at: www.pearsoned.co.uk/psychologyexpress

Defining death**Biological death**

- Death is hard to define as it is not a single event but a process.
- Different body systems die at different rates.
- Death was once defined as having no heartbeat/pulse or no longer breathing.
- However, some individuals who lack a pulse or are not breathing can now be revived before their brains cease to function and kept alive by artificial life support systems.
- The UK, unlike many other countries, does not have a legal definition of death. Guidelines for the diagnosis and confirmation of death are purely medical and are provided by the Academy of Medical Royal Colleges (AMRC).
- Medical guidelines are mainly concerned with confirmation of death in hospital and in circumstances where the diagnosis of death may be more difficult (patients on ventilators, for example).
- Medical guidelines rely on a diagnosis of brain death.
- However, this is not based on whether or not the heart is still beating and, while in most cases this function will cease once withdrawal of life support systems occurs, many people still see a beating heart as indicative of life.
- It has therefore been argued that these decisions should include a more social element in order to ease the burden on the family of the dying (Kellehear & O'Connor, 2008).

Social meanings of death

- As Kellehear has noted, death is a psychological and social as well as a biological process.
- The social meaning attached to death has changed across the course of history (Aries, 1981). In contrast to the middle ages, when individuals were

encouraged to recognise their own mortality and prepare for death with dignity, Western society today engages in a denial of death.

- Death has been removed from the home in the UK and familiarity with death has decreased considerably since the 1900s, when most people died in their own homes (Thorpe, 1993).
- Some 200 years ago, the death rate was such that half of all children died before the age of 10 years and one parent usually died before a child grew up. Nowadays, many people do not experience the death of someone close to them until they are well into midlife (Department of Health, 2008).
- It is perhaps not so surprising, therefore, that, as a society, death and dying are subjects not openly discussed (Kellehear, 2005).
- Surveys have shown that, given the opportunity and support, most people would prefer to die at home, yet in practice only a minority are able to do so (Department of Health, 2008): many people (58 per cent) die in acute hospital settings, which are often not their preferred place of care.
- Much of the responsibility for end-of-life care is given over to hospice and palliative care services (Kellehear, 2005).
- According to Kellehear (2005), this type of care emphasises the person as an individual and therefore the focus is placed on providing services to them as patients within these institutions or as patients at home.

Key term

Brain death: this medical definition of death focuses primarily on irreversible brain stem damage and notes that in the absence of neurological functioning 'the patient is dead even though respiration and circulation can be artificially maintained successfully for a limited period of time' (AMRC, 2008: 13). A diagnosis of brain death is made using factors such as fixed and dilated pupils, lack of eye movement and the absence of respiratory reflexes. This definition is important because it has been argued that the current emphasis on brain death is at least in part driven by the need to harvest (healthy) organs for transplant. Because it is clinically based, this definition takes no account of the emotional and social aspects of death, treating it as a purely biological phenomenon. From a psychological perspective this has implications for the bereaved family.

Test your knowledge

- 11.1 What is the medical definition of death in the UK?
- 11.2 How does this differ from how most of us perceive death?
- 11.3 How have the experiences of death and dying changed over time?

Answers to these questions can be found on the companion website at: www.pearsoned.co.uk/psychologyexpress

Further reading End-of-life care

Topic	Key reading
Medical definitions of death	Seale, C. (2009). End-of-life decisions in the UK involving medical practitioners. <i>Palliative Medicine</i> , 23(6), 198–204. Available online at: www.eutanasia.ws/hemeroteca/t301.pdf

End-of-life care**Hospice care**

The term 'hospice' is rooted in the idea of offering 'hospitality', such as shelter and a place to rest, to sick and weary travellers. The term was originally applied to specialised care for dying patients in 1967 by Dame Cicely Saunders at St Christopher's Hospice in London. There are many positive aspects to the hospice movement. The philosophy is one of caring rather than curing and the aim of this care is to help people find meaning in death (Clarke, 2002). This is just one difference between hospice and hospital care. Other features of hospice care include:

- treating the patient, not the disease
- focusing on quality, rather than quantity, of life
- however, this does not mean that there is ever any intention to shorten life; euthanasia is not promoted by the hospice movement
- pain control emphasis on, ensuring prevention and relief of symptoms
- hospice staff providing direct care to the patient or teaching the family to care for the patient between visits if care is provided in the patient's home
- social issues, such as ensuring that the patient designates a surrogate decision-maker and makes advance plans, plus hospice staff preparing patient and family for the time near death (Lynn, 2001)
- the individual and their family, not the experts, deciding what support they need
- care being kept as 'normal' as possible (preferably in the patient's own home)
- support being provided for family members as they go through the grieving process
- bereavement counselling being provided before as well as after death.

Research suggests that the benefits of hospice care include less pain at the end of life, fewer medical interventions and care more aligned to individual emotional needs (Seale, 1991). There also appear to be benefits for the family, including better well-being and fewer symptoms of grief (Ragow-O'Brien et al., 2000).

Compassionate Communities

Kellehear (2005) argues that a person must be seen not just as an individual but also as a social being, intricately connected to a community of friends, family and co-workers. This philosophy underpins the health promoting palliative care movement, which emphasises community-based care for people with life-threatening illnesses (Mitchell, 2008). This movement has already had some success in Australia where it originated and the approach is currently being explored in some regions of the UK under the name 'Compassionate Communities'.

- Compassionate Communities is a movement within the UK that believes the special needs of those living with life-threatening illness and those living with loss should be met through a supportive community rather than through the provision of centralised services.
- Individuals within a community are provided with an opportunity to work together alongside healthcare professionals.
- According to Kellehear (2005), the aim is to:
 - create more unity within the community
 - empower the community to support themselves using the resources available to them
 - increase social capacity and resilience towards experiences of dying, death and loss
 - promote quality of care in end-of-life care.

Test your knowledge

11.4 What are the main benefits of hospice care?

11.5 How do Compassionate Communities aim to improve end-of-life care?

Answers to these questions can be found on the companion website at:

www.pearsoned.co.uk/psychologyexpress

Further reading End-of-life care

Topic	Key reading
End-of-life care in the UK	Riley, J. (2008). A strategy for end of life care in the UK. <i>British Medical Journal</i> , 337, a943.
Compassionate Communities	Kellehear, A. (2000). Spirituality and palliative care: A model of needs. <i>Palliative Medicine</i> , 14(2), 149–155.

Bereavement, grief and loss

- Bereavement – that is, the loss, through death, of loved ones – can occur at any stage of life.
- Grief is the emotional response to loss.
- The observable expression of grief is called *mourning*.
- We have to recognise that grief can begin before the actual death and those dying can also grieve their own loss.
- The grieving process is dependent upon the relationship with the person, factors surrounding the loss (for example, sudden or impending), as well as unresolved issues with the deceased.
- Bereavement is a normal part of life, but carries high risk when no support is available.
- Severe reactions to loss may carry over into familial relations and cause trauma for children and spouses. For example, there is an increased risk of marital break-up following the death of a child.
- Loss of a child is often described as one of the most difficult deaths to adjust to: parents do not get 'over' the loss but instead learn to assimilate and live with death (Davies, 2005). It is thought that the dependent nature of the relationship, coupled with normal experiences of grief, can be overwhelming.
- Such factors influence whether a person will go through a 'normal' or 'abnormal' grieving process. For example:
 - death resulting from an accident, rather than from a long terminal illness where individuals have been told that their family member or friend will die, increases the likelihood of there being an abnormal grieving pattern.
 - death in old age is often negotiated more easily by families, as it is seen as more 'natural' than when a child, teenager or young adult dies, even if they were terminally ill.

Models of grief

According to Archer (1999), a widely held assumption is that grief proceeds through an orderly series of stages or phases with distinct features. Traditional models have one main commonality: the need for grief work, which is described as, 'an effortful process that we must go through entailing confrontation of the reality of loss and gradual acceptance of the world without the loved one' (Stroebe, 1998).

- Models of grief and loss emphasise that all individuals will experience particular emotional and physical states, but will vary as to the amount of time that is spent at each stage.

- All models emphasise the need to experience these stages in order to reach acceptance.
- Grief work models can be applied to the grief process that both adults and children will go through before reaching acceptance, although as the next section shows age will impact on how grief is displayed.
- Parkes' (1972; 1986) four-stage model describes the phases of bereavement and, in turn, grief work that an individual faces (see Table 11.1). According to this model, an individual has to work through the stages of grief in order to reach acceptance and move forward in life.
- More recent empirical work provides some support for these different aspects of grief (Maciejewski et al., 2007).

Table 11.1 Parkes' four-stage model of grief work

Name of phase	Reactions, emotions in each phase
Phase One	Initial reaction: shock, numbness or disbelief
Phase Two	Pangs of grief, searching, anger, guilt, sadness and fear
Phase Three	Despair
Phase Four	Acceptance/adjustment. Gaining a new identity

Source: based on Parkes (1986)

According to the World Health Organization, the need to offer family and significant others support, not only during the patient's terminal illness but also in bereavement, is significant and provides the contemporary philosophy of palliative care (WHO, 1990). Research (for example, Herkert, 2000) suggests that bereaved individuals are most helped by those who:

- say they are sorry for their loss
- make themselves available to serve as confidants
- let the bereaved express the painful feelings freely when they are ready.

It is less helpful when individuals:

- tell people how they should feel and cope, rather than simply asking how they are and how they are coping
- try to emphasise the positives, with comments such as 'At least he had a good innings' or 'At least he is no longer suffering', as such remarks may be well-intentioned, but are often not well received by those dealing with loss.

Grief responses across the lifespan

There are enormous differences in children's understanding of loss and how they cope with bereavement. This has often been understood in terms of the children's cognitive development. Table 11.2 indicates the different grief reactions a child may exhibit dependent on their age.

Table 11.2 Grief and developmental stages

Age	Understanding of death	Behaviour/expression of grief
Infants	<ul style="list-style-type: none"> Do not recognise death Feelings of loss and separation are part of developing an awareness of death 	<ul style="list-style-type: none"> Separated from mother – sluggish, quiet, and unresponsive to a smile or a coo Physical changes – weight loss, less active, sleep less
2–6 years	<ul style="list-style-type: none"> Confuse death with sleep Begin to experience anxiety by age 3 	<ul style="list-style-type: none"> Ask many questions Problems in eating, sleeping and bladder and bowel control Fear of abandonment Tantrums
3–6 years	<ul style="list-style-type: none"> Still confuse death with sleep, i.e., is alive but only in a limited way Death is temporary, not final Dead person can come back to life 	<ul style="list-style-type: none"> Even though saw deceased buried, still ask questions Magical thinking based on lack of knowledge – his or her thoughts may cause someone to die Under 5 – trouble eating, sleeping and controlling bladder and bowel functions Afraid of the dark
6–9	<ul style="list-style-type: none"> Curious about death Death is thought of as a person or spirit (skeleton, ghost, bogeyman) Death is final and frightening Death happens to others; it won't happen to me 	<ul style="list-style-type: none"> Ask specific questions May have exaggerated fears May have aggressive behaviours (especially boys) Some concerns about imaginary illnesses. May feel abandoned
9 yrs +	<p>Everyone will die Death is final and cannot be changed Even I will die</p>	<ul style="list-style-type: none"> Heightened emotions, guilt, anger, shame Increased anxiety over own death Mood swings Fear of rejection, not wanting to be different from peers Changes in eating habits Sleeping problems Regressive behaviours (loss of interest in outside activities) Impulsive behaviours Feels guilty about being alive (especially related to death of a parent, sibling or peer)

Source: based on National Cancer Institute, U.S. National institutes of health <http://www.cancer.gov/cancertopics/pdq/supportivecare/bereavement/Patient/allpages/>

- Adolescents have a much clearer understanding of death and are more likely than younger children to recognise death as an inevitable biological process.
- However, despite this knowledge, there is evidence that many adults and adolescents share the belief of children that psychological functions such as knowing and thinking continue even when biological functions have stopped (Bering & Björklund, 2004), demonstrating a belief in an afterlife.

- Adolescents tend to grieve in much the same way that adults do, but may be reluctant to express their grief for fear of seeming abnormal or lacking in control.
- They may therefore express their anguish through delinquent behaviour and somatic ailments (Clark, Pynoos, & Goebel, 1994).

CRITICAL FOCUS

How can we help the grief process?

Read the scenario provided below and answer the question that follows.

Jim, his wife Rose and their three children were overjoyed at the news that Rose was expecting a baby. A couple of months into the pregnancy, Rose was unexpectedly taken into hospital with severe abdominal pains and bleeding. A few hours later, the couple had their worst nightmare confirmed: Rose had had a miscarriage. Both were shocked by the news. The senior staff nurse noticed that both Rose and Jim were finding it difficult to come to terms with the miscarriage and decided to help the couple with their grief, so that coming to terms with the miscarriage would be easier for both of them. The senior staff nurse introduced herself and said how sorry she was for the couple's loss. Rose looked at the nurse with a blank expression, while Jim replied that they would be fine and they could do nothing about it now. Rose was kept in hospital for a couple of days until her health became more stable. During her stay, the senior staff nurse and others encouraged Rose to talk about her feelings, but Rose did not reveal any of her emotions or feelings. Three days later Rose's physical health had improved and she was prepared for discharge. Knowing that Rose would be discharged, the nurse decided to talk to Jim and explain her concerns that Rose had shown no emotion. She gave Jim a leaflet listing organisations offering further support for Rose. When Jim became tearful, the nurse reassured him that the grieving process would become easier over time. She further emphasised the positive things in life that they needed to focus on, such as their three children, comparing their situation to those of others who have miscarried and have no children. Jim began to feel guilty about being upset and thanked the nurse for her help and concern.

Does the staff nurse help or hinder grief work?

Models of loss

Elizabeth Kübler-Ross was one of the first researchers to study patients and their families from the time of the diagnosis of a terminal illness up until death. This research resulted in more emphasis being given to palliative care and quality of life, even if a patient will die. Kübler-Ross suggested a five-stage model for the experience of dying, which has provided a framework for those working with individuals experiencing personal loss (see Table 11.3).

It is often assumed that terminally ill young children are unaware that they will die and are better off remaining that way. However, evidence shows that even preschool children with life-threatening illnesses such as leukaemia come to understand that they will die and death is irreversible (Bluebond-Langner, 1977).

Table 11.3 Kübler-Ross' five-stage model (1969)

Stage	Example	Explanation
Denial and isolation	'No, not me' or 'It can't be me – you must have the results mixed up'	During this stage there is constant denial of the new status a patient or family are prescribed. Denial acts as a buffer system, allowing the patient to develop other coping mechanisms. It can also bring isolation and the patient may fear rejection and abandonment in suffering and feel that nobody understands what the suffering is like
Anger	'It's not fair – why me?'	This is a stage when anger is taken out on practitioners such as nurses (and also on doctors, relatives or other healthy people). Typical reactions are, 'Because of you (the nurse), I can't go home and pick my children up from school' or 'Because of you (the nurse) I have to take time out so you administer pain to me' or 'It's OK for you; you can go home at the end of the day.' There is a shift from the first stage from 'No it can't be me it must be a mistake' to 'Oh yes it is me; it was not a mistake'
Bargaining	'Please God let me...'	This is an attempt to postpone death by doing a deal with God/fate/hospital. At this stage, people who are enduring a terminal illness and looking for a cure or 'a bit more time' will pay any price and will usually be manipulated at this stage. It is not uncommon for patients who have never been religious now to turn to religion – almost bargaining again – 'If I pray you will grant me another extra couple of days'. The problem is that even when a couple of extra days are granted, these are never enough; the patient wants more
Depression	'How can I leave all of this behind?'	This time is very much a quiet, dark and reflective time. It is very similar to someone actually experiencing depression. During this stage, the dying patient does not want reassurance from a nurse, but at the same time does not want to be ignored. During this time family members of the dying patient begin the five-stage model and so are very much attempting to be proactive – that is, in denial that the family member is going to die. They may even become angry at the patient for 'giving up'. The dying patient during this stage would like people around them to be quiet and this is where nurses can make a difference. All they want is for someone to be present, who does not question and is not angry. There will be questions the patient will ask and they need to be answered honestly (especially because they don't have to pretend to be strong away from the family). In addition to this, the patient during this stage would also like the nurse to anticipate questions

Table 11.3 Continued

Stage	Example	Explanation
Acceptance	'Leave me be, I am ready to die'	This stage is where the individual is neither depressed nor angry. He or she has worked through feelings of loss and has found some peace. During this stage the patient has accepted his or her situation and is ready to go. Also within this stage, family members are very angry or questioning why the patient is at peace when they still want to change the status of the patient. The patient, however, has begun the process of letting go during the depression stage and has now finished this process and accepts the inevitable. He or she is ready to move on

- Over time, terminally ill children stop thinking about the future and focus on the here and now.
- Children experience the same emotions in death as adults – fear, anger, sadness and, finally, acceptance.
- Preschool children may not talk about dying, but they can reveal their fears through temper tantrums.
- School-age children are better able to talk about their fears and there is evidence that talking to a child about their death can be beneficial, both for the child and the parents, if the child shows the desire to do so (Faulkner, 1997).
- School-age children often show a desire to continue with everyday activities, such as going to school for as long as possible, so as to feel 'normal'.
- The response of the adolescent to becoming terminally ill clearly reflects the developmental tasks of this period (Stevens & Dunsmore, 1996).
- The focus is often on body image, meaning that body changes such as weight gain or loss of hair will provoke feelings of distress.
- In the same way, a loss of identity can be felt when new-found independence is taken away on account of the reliance on parents and healthcare professionals that illness may bring.

Cultural differences in grieving

Sometimes a distinction is made between *grief* and *mourning*. Grief is seen as a subjective state, a set of feelings that arise spontaneously after a significant death, whereas mourning describes the way in which grief is displayed, which is often constrained by the rituals or behaviours prescribed by a culture.

- The Western approach to bereavement is not universal. Displays of grief and mourning take different forms across the world and are often heavily influenced by religion (Chachkes & Jennings, 1994).
- Funerals may be an occasion for avoiding people or for holding a party (Metcalfe & Huntington, 1991).

- Most societies have some concept of spiritual immortality, yet even here there are cultural differences, ranging from the idea of reincarnation to the concept of ancestral ghosts who meddle in the lives of the living (Rosenblatt, 1993).
- Some cultures, especially those in Latin America, believe that mourning involves the display of intense, hysterical emotions that should be shared with the community (Cook & Dworkin, 1992), while others, such as the British, restrain their grief so as not to burden others.

Key terms

The terms grief, bereavement and mourning are often used as synonyms, but they all have different meanings.

Grief: is the normal process of reacting to any form of loss. Grief may be a reaction to physical loss, such as death, or in response to a social loss, such as divorce or loss of a job. Grief can be displayed physically, emotionally, cognitively and socially.

- Physical reactions may include eating and sleeping problems.
- Mental reactions may include anxiety, sadness and despair.
- Social reactions include readjusting to life without the deceased or readjusting to life after the diagnosis of a terminal illness.

Grief processes depend on the relationship with the person who died, the situation surrounding the death and the person's attachment to the person who died.

Bereavement: the period after a loss during which grief is experienced and mourning occurs. The time spent in a period of bereavement depends on how attached the person was to the person who died and how much time was spent anticipating the loss.

Mourning: the process by which people adapt to a loss. Mourning is also influenced by cultural customs, rituals and society's rules for coping with loss.

Test your knowledge

- 11.6 What are the differences between bereavement, grief and mourning?
- 11.7 What are the four phases of Parkes' model of grief?
- 11.8 Discuss how age affects displays of grief and feelings of loss.
- 11.9 How might an adolescent use behaviour to express their grief?

Answers to these questions can be found on the companion website at:
www.pearsoned.co.uk/psychologyexpress

? Sample question

Essay

How might the Kübler-Ross model of dying be applied in a hospice with terminally ill adults?

? Sample question

Information provider

Design a resource for parents and other carers with information about the impact of bereavement on children of different ages. What are the key issues they need to know? How can you help parents identify feelings of loss in their child?

Further reading Bereavement, grief and loss

Topic	Key reading
Models of grief	Maciejewski, P. K., Zhong, B., Block, S. D., & Prigerson, H. G. (2007). An empirical examination of the stage theory of grief. <i>Journal of the American Medical Association</i> , 297(7), 716–723.
Grief therapy	Neimeyer, R. A., & Currier, J. M. (2009). Grief therapy: Evidence of efficacy and emerging directions. <i>Current Directions in Psychological Science</i> , 18, 352–356.
Loss of a child	Davies, R. (2005). Mothers' stories of loss: Their need to be with their dying child and their child's body after death. <i>Journal of Child Health Care</i> 9(4), 288–300.

Quality of life and the right to die

The letters 'DNR' written on a patient's file indicate that a doctor is not required to resuscitate a patient if their heart stops. Standing for 'do not resuscitate' these three letters are designed to prevent unnecessary suffering.

- For terminally ill patients, the letters DNR may be the difference between dying immediately or being kept alive through extreme, possibly painful, medical procedures, for days, weeks or even months.
- DNRs are therefore sometimes seen as a form of *euthanasia*, the practice of assisting someone to die more quickly.
- Sometimes called 'mercy killing', euthanasia takes one of two forms:
 - *passive euthanasia* – death is hastened because of the withdrawal of care (for example, switching off a life-support machine) or non-intervention (for example, following a DNR order)
 - *active euthanasia* – involves deliberately acting to end a person's life by, for example, administering a fatal dose of pain medication.
- Euthanasia is an emotive subject and people often have firm views on whether such a practice is right or wrong.

- Some people make a moral distinction between active and passive euthanasia, arguing that it is acceptable to withhold treatment and allow a terminally ill patient to die, but not to kill someone by a deliberate act.
- Others argue that this distinction is unfounded, since both letting someone die and actively killing someone result from a deliberate act, the intended outcome of which is someone's death.
- Active euthanasia is illegal in most countries, including the UK, but one study suggests that almost half of NHS doctors have been asked by a patient to take active steps to hasten death and a third of those asked complied with the patient's request (Ward & Tate, 1994).
- In the UK, the British Medical Association (BMA) and the Royal College of Nursing (RCN) and the Resuscitation Council (UK) have provided guidelines on the use of DNR orders and are clear that these should only be issued after discussion with patients or their families.
- The most difficult cases are those involving patients who know they are terminally ill, are suffering a lot of pain, but who could live for several months.
- The BMA guidelines state that circumstances in which a DNR may be issued include:
 - when a patient's condition is such that resuscitation is unlikely to succeed
 - when a mentally competent patient has consistently stated that he or she does not want to be resuscitated
 - if there is a *living will*, which says the patient does not want to be resuscitated
 - if successful resuscitation would not be in the patient's best interest because it would lead to a poor quality of life (QoL).

The final point raises an important issue: at what point does life cease to have 'quality' and who decides that an individual's life is no longer worth living? Two main issues have been found to be important in determining terminal patient's QoL (Shahidi, Bernier & Cohen, 2010):

- the patient's physical and mental state
- the relationships and support provided by others.

Normally QoL is judged by the individual themselves, as QoL is defined by our subjective experiences, states and perceptions (Burckhardt and Anderson, 2003).

- However, some have questioned whether a terminally ill patient is always capable of judging the quality of their life.
- This raises a new question: if the patient is found incapable of judging their life quality, then who should – a family member, a medic or other healthcare professional?
- Consideration of QoL is closely linked to decisions about what is in an individual's best interests.

- The challenge is to define what a person's best interests are and how they can best be met: can someone's best interests ever be met by withdrawing or administering a particular treatment?
- Advocates of euthanasia argue that it is not in the best interests of a terminally ill patient to suffer pain needlessly when their life is close to the end.
- The failure to end that suffering, even if the only way of doing so is to intentionally end the patient's life, is seen as going against the duty of the health professional to do what is best for the patient's well-being.

Key terms

Quality of life (QoL): is a complex concept, which concerns an individual's satisfaction with all aspects of their life from the physical to the social and psychological. Many things can affect QoL, including income, social and physical environment, interpersonal relationships and health. QoL is subjective and so can be known only to the individual concerned. It is now widely accepted that it is important to understand and improve the QoL at the end of life. One concern in medicine today is that we can improve the length of people's lives, but we do not always know at what cost. However, trends in QoL at the end of life are poorly understood because of the difficulty in finding out such information.

Test your knowledge

- 11.10 What does DNR stand for?
 11.11 Is there a difference between active and passive euthanasia?
 11.12 How is quality of life (QoL) usually defined?
 11.13 What are the main issues surrounding QoL in terminally ill patients?

Answers to these questions can be found on the companion website at:
www.pearsoned.co.uk/psychologyexpress

? Sample question

Problem-based learning

Rachel was diagnosed with a brain tumour at the age of eight years. Now aged 12, she has spent the past 4 years in and out of hospital undergoing a range of treatments, including chemotherapy and radiation, but the tumour shows no signs of going away. The location of the tumour makes it inoperable and the family has all but given up hope of a cure. However, a new chemotherapy treatment has recently become available in England and is being trialled at the children's hospital where she is treated and her consultant has asked if Rachel would like to be included in the trial. Rachel and her family have been told that the treatment has a 50 per cent chance of success, but this is the only treatment left open to Rachel. Rachel herself

has refused this treatment. She explained to the consultant that she has had enough of hospitals, needles and being poked and prodded. She does not want to be a guinea pig for some new treatment that might not even work. All she wants is to be able to spend time at home with her family. She accepts that refusing this treatment means she will probably die within a few months, but thinks the chances of success are not a good enough reason for spending more time in hospital undergoing painful treatment. She has stated that if she is going to die anyway she would rather do so at home. Her mother is upset by this turn of events, but says she understands Rachel's reasoning and will support her decision.

Should Rachel be allowed to decide that she no longer wants any treatment? Based on your knowledge of cognitive development, at what age should someone be deemed able to make their own decisions?

Is Rachel's mother right to support Rachel's decision or should she force her child to be treated?

Further reading Quality of life and the right to die

Topic	Key reading
Attitudes to euthanasia	Ward, B. J., & Tate, P. A. (1994). Attitudes among NHS doctors towards requests for euthanasia. <i>British Medical Journal</i> , 308, 1332-1334. Available online at: www.bmj.com/content/308/6940/1332.full
QoL	Diehr, P., Lafferty, W. E., Patrick, D. L., Downey, L., Devlin, S. M., & Standish, L. J. (2007). Quality of life at the end of Life. <i>Health and Quality of Life Outcomes</i> , 5, 51. Available online at: www.hqlo.com/content/5/1/51

CRITICAL FOCUS

Interpreting statistics: changing mortality rates in the UK 1971-2006

Figure 11.1 shows mortality rates for the UK in 2006. What does this data tell you about:

- differences in male and female death rates in 2006?
- age-related trends in mortality rates in 2006?

At what ages are male and female mortality rates similar? Why do you think we see this pattern?

The patterns shown in Figure 11.1 reflect those described at the start of this chapter: females show lower mortality rates throughout most of the lifespan when compared to males; mortality rates drop after infancy, then do not start to increase until middle adulthood (35-54); the highest increase in mortality is seen in old age. .

Figures 11.2 and 11.3 show the mortality rates for males and females over 30 years.

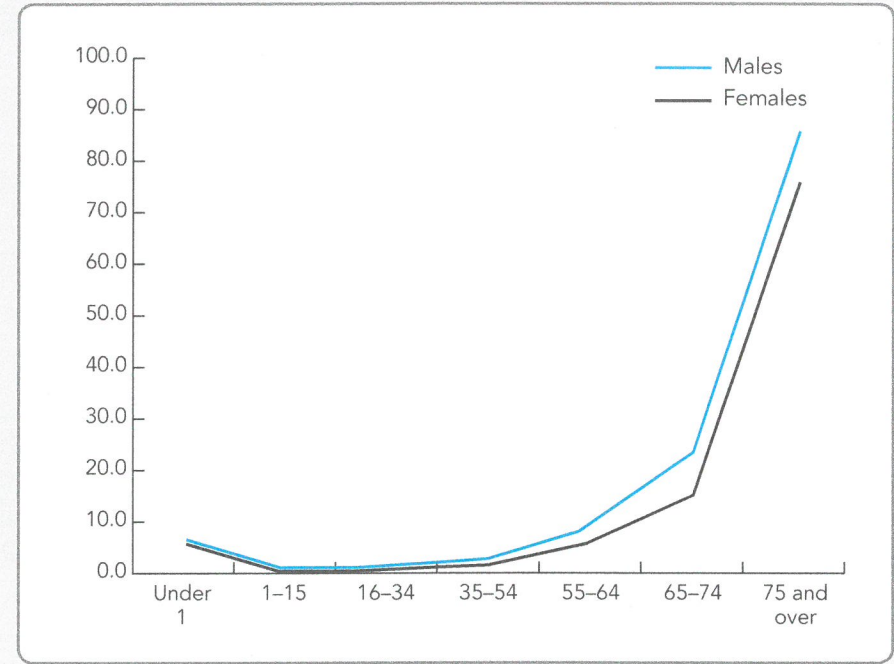


Figure 11.1 Mortality rates per 1000 in the UK in 2006

Source: adapted from data from the Office for National Statistics licensed under the Open Government Licence v.1.0

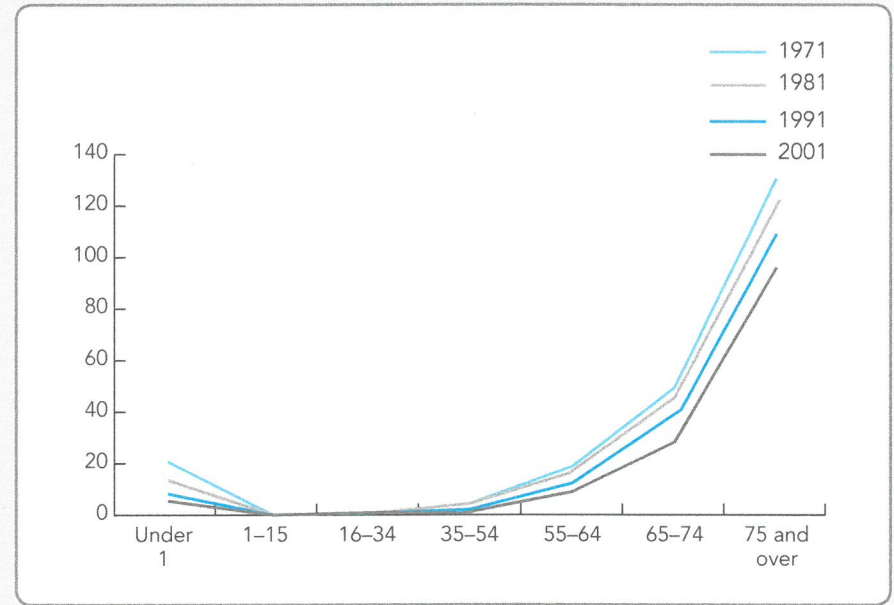


Figure 11.2 Male mortality rates per 1000 in the UK, 1971-2001

Source: adapted from data from the Office for National Statistics licensed under the Open Government Licence v.1.0

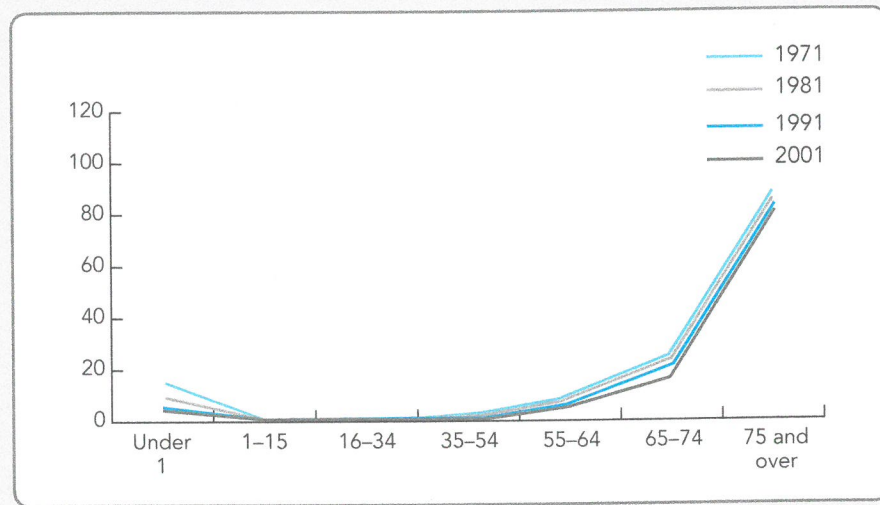


Figure 11.3 Female mortality rates per 1000 in the UK, 1971–2001

Source: adapted from data from the Office for National Statistics licensed under the Open Government Licence v.1.0

Compare these graphs in order to answer the following questions.

- What differences can you see in the changes to male and female mortality rates from 1971 to 2001? Why do such differences exist?
- When was the biggest change to infant mortality rates for both males and females? Think back to Chapter 2: what factors do you think are most associated with high infant mortality?

The data spanning 1971–2001 demonstrates another issue raised at the start of the chapter – the reduction in the gap between male and female mortality rates. While life expectancy continues to increase for both males and females, a greater increase is seen in male life expectancy. This is thought to relate to improvements in prevention and treatment of life-limiting diseases experienced mainly by males, such as heart disease. Infant mortality rates appear to have reduced the most between 1971 and 1981, although a gradual decline is still seen from 1981 to 2001. A range of social and biological factors are associated with high infant mortality, including low birth weight, which often links to maternal behaviours such as smoking and drinking. Other factors include multiple births, marital status, age of mother, country of birth of mother and father's social class. Social class differences in infant mortality rates are wider in the post-neonatal period (deaths between 28 days and a year) than the neonatal period (deaths under 28 days). According to Norman et al. (2008), health inequalities in infant mortality remain between different social groups. The initial rapid decline seen in this data set is therefore thought to be related to a general reduction in health inequalities in the early 1970s and 1980s (Norman et al., 2008). Further reduction in 1981–1991 is thought to be related to the 'Back to Sleep' campaign that encouraged parents to put their baby to sleep on their backs, which reduced the number of sudden infant death syndrome (SIDS) deaths.

Chapter summary – pulling it all together

- ➔ Can you tick all the points from the revision checklist at the beginning of this chapter?
- ➔ Attempt the sample question from the beginning of this chapter using the answer guidelines below.
- ➔ Go to the companion website at www.pearsoned.co.uk/psychologyexpress to access more revision support online, including interactive quizzes, flashcards, You be the marker exercises as well as answer guidance for the Test your knowledge and Sample questions from this chapter.

Answer guidelines

* Sample question

Essay

Evaluate the importance of social, cultural and developmental influences on our beliefs about death, dying and bereavement.

Approaching the question

Your answer should aim to provide an analysis of how personal experiences, the wider social context and developmental level help determine how individuals will respond to loss. You should aim to consider how individuals respond to knowledge of their own death as well as loss of a significant other. Remember that even though death has a clear biological component, this is not the only factor to influence what we believe – there are also social and emotional definitions.

Important points to include

- Begin by defining the main issue, which is that while there are medical definitions of death based on biological processes, this is not how most people define death.
- Compare and contrast medical and social definitions of death, remembering to discuss the way the social context has impacted on definitions of death. You might want to look at factors that change what we believe about death, such as:
 - historical context
 - cultural norms
 - religious beliefs.

- You should then look at the way in which, even in a specific social context, individual differences are important to our beliefs about death and bereavement. You will need to consider:
 - developmental stage/age
 - nature of the loss, for example:
 - own life or that of another person
 - sudden or expected loss
 - age of/relationship to the deceased
 - personal experiences of death and illness.
- Remember to link these ideas to other areas of developmental psychology you have studied, such as how aging affects readiness for death and children's cognitive development. This will demonstrate your ability to provide a synthesis of the many aspects of developmental psychology.

Make your answer stand out

It is really easy just to take a descriptive approach in which you outline the differences between social and medical definitions of death, age-related responses to bereavement, etc. A good answer will remember to take a critical stance, evaluating the links between contextual and individual factors. At a societal level, for example, beliefs about death are changing because of increases in medical knowledge. How might this also affect beliefs at an individual level? You might expect that someone educated in medicine, for example, because of their specialist knowledge, will respond differently to knowing that their loved one is brain dead, compared to someone without that training. However, we also know that interpersonal relationships affect how we interpret information – might a social and emotional response outweigh an intellectual one? Will that response be different depending on the age of the loved one or the nature of the relationship? Acknowledging complexities such as this and carefully analysing them, rather than presenting grief responses simplistically, will really make your answer stand out.

Explore the accompanying website at www.pearsoned.co.uk/psychologyexpress

- Prepare more effectively for exams and assignments using the answer guidelines for questions from this chapter.
- Test your knowledge using multiple choice questions and flashcards.
- Improve your essay skills by exploring the You be the marker exercises.

Notes