

## Chapter 7

# Psychological aspects of care

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### INTRODUCTION

In managing any physical health problem it is important to consider not only the biological mechanisms involved in the disease process but also the impact of that condition on the individual person, and the extent that the individual person influences the process of the illness. This broader approach to managing an illness is based on the biopsychosocial model (Engel 1980), which recognizes that an individual's psychological and social worlds are key influences on both the process and management of illness. An illustration of this is the patient with coronary heart disease whose behaviour of smoking, eating a high-fat diet and living a stressful lifestyle may contribute to both development and progression of the disease. This approach to health problems contrasts with the more traditional biomedical model which views illness management purely in terms of the biological mechanisms at work. This chapter therefore aims to discuss some of the key psychological and social issues pertinent to cardiac and respiratory conditions. In doing this an illness trajectory approach i.e. from diagnosis to death, is taken with issues specific to both paediatric and adult populations highlighted throughout.

### GIVING A DIAGNOSIS

There is a great deal of anxiety among health care professionals at the prospect of holding a meeting with a patient or parents to give a medical diagnosis. The anxiety stems from anticipation of the reactions produced by the bad news. The prediction is that the recipients will display high levels of distress and the deliverer of the bad news will be the target of their emotions. It is important to remember that the meeting to disclose

diagnosis has a very specific purpose and there is no need to ensure that all angles are covered at this first meeting. The patient and/or parents are unlikely to remember much about the content of the meeting and more about the manner in which the information was given (Brewin 1991, Bush 2001, Quine & Pahl 1986). There has been much written on how to deliver 'bad news' but it is important to remember that there are two key aims for the content of the disclosure meeting:

1. To clearly state the confirmed diagnosis.
2. To inform about immediate treatment plans.

Much of the information given will not be taken in initially; it can be given at follow-up meetings when the patient/parents are ready for it and when it is relevant to their own or child's needs.

### Impact of diagnosis in childhood

Diagnoses of cardiorespiratory conditions made within the first few months of life have a particular impact as they come at a time when parents are feeling intense emotions towards their newborn infant, and they are asked to assimilate the information that their baby has a potentially life-limiting illness such as cystic fibrosis (CF) or heart problems. Parents who had been prepared for acquiring childrearing skills now must learn nursing and medical skills and incorporate a group of uninvited strangers comprising the medical team. Clearly, this time will be one of stress and sorrow for parents and a frequently asked question is: 'Does a diagnosis of a medical condition given early in the child's life carry with it a risk for damage to the parent-child bond?'

Simmons et al (1995) conducted a study to evaluate whether the mother-child bond was affected when the child has CF. They used Ainsworth et al's (1978) gold standard assessment of mother-child attachment, which examines the infant's behaviour following separation and reunion with mother, to compare a group of children with CF against healthy controls. Their findings revealed that the majority of infants (60.5%) demonstrated a secure attachment with mother, with some showing an insecure-avoidant pattern where the child shows little distress on separation and actively avoids the mother on reunion. A small number show insecure-resistant patterns where the child shows extreme distress on separation and then a mixture of contact and rejection on reunion, generally being very unsettled. There were no significant differences in rates of insecure attachments found from the healthy controls, but the implications are that those children with insecure attachments to a primary caregiver will be vulnerable at times of stress.

This suggests that the parent-child instinctive drives to form a bond are not affected by the diagnosis of CF and the same could be said to be true for other cardiorespiratory conditions. Concerns have been raised that the infant diagnosed with CF via newborn screening techniques may harm the mother-child attachment by disrupting the relationship with the disclosure of a life-threatening illness in an infant that had not displayed any symptoms of disease (Young et al 2001). Studies that have begun to examine that question have found no evidence to support this hypothesis (Boland & Thompson 1990). It has been reported, however, that mothers of children diagnosed by newborn screening have higher frequencies of 'at-risk' scores for parenting stress than mothers of traditionally diagnosed children (Baroni et al 1997) though these authors suggest that the significant variables influencing maternal well-being are the way in which the diagnosis is communicated and subsequent parental support.

Parents of children with a medical condition are at risk for over-protection of their children. A fear of infection can result in parents restricting the physical movements and toys of their young children. Attendance at playschools and nurseries may be denied; possibly even contact with other healthy children may be limited. Studies of the play interactions of parents of preschool children with CF indicate that mothers are much more interfering and less supportive of their children and the child correspondingly shows less persistence and compliance in play activities (Goldberg et al 1995). The child-rearing practices of parents of children with CF may be affected by the overwhelming need to protect the child. All daily interactions from dressing to feeding to bedtimes may be indirectly altered by the diagnosis.

### Talking to children about their diagnosis

Originally, developmental theorists sensibly proposed that a child's understanding of illness would follow a stage approach mirroring the stages of intellectual development proposed by Piaget (1952). Bibace & Walsh (1980) proposed a six-stage approach from phenomenism at the first stage where the child believes that illness is spatially remote from the person who has the illness to the most advanced stage – termed psychophysiological – in which children recognize an interaction between physical and psychological health. As such, a child in the preschool years would be considered as capable only of concrete operations; i.e. their thought processes are tied to the immediately observable cause and effect relationships. Their understanding of illness arises from observed links: when unwell, see the doctor, who will give medicine that will make you better. There is no concept that the illness is physically within them. Clearly, within this theoretical framework

there is no room for a concept of illness *prevention*, which is the level of understanding required for an illness like CF; you are well but take this medicine to prevent you from being ill.

Anecdotal reports that young children with chronic illnesses have developed a precocious comprehension of their own condition and have a much more competent understanding of illness has led to a re-consideration of the applicability of the stage theory which appears too simplistic (Kalish 1996, Springer 1994, Springer & Ruckel 1992). For sick children a more comprehensive understanding of their medical condition comes about by virtue of their frequent experience with hospital and illness (Eiser 1989). Studies have found that even young children can understand and operate the concept of contagion as originating from invisible sources and they can accept germs causing illness (Eiser 1989, Rosen & Rozin 1993) though they do not fully understand the causal processes (Soloman & Cassimatis 1999).

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Children with chronic illness are capable of a more sophisticated understanding of their illness than previously thought. However, there is a barrier to effective communication with children. On interview about their condition, children with CF tend to give consistently similar responses to questions irrespective of age; they know that CF affects the respiratory (85%) and digestive (80%) systems, though don't know why or how and the majority don't know the importance of nutrition (70%) (Angst 1993). This suggests that they are repeating received information without assimilating true understanding. Children tend to hold a glossary of CF terms that is separate from how it affects them personally. Although they are quite capable of a decent knowledge of their own health and engage in patient-clinician discussions about treatment, the tendency is to avoid this. Children with CF define themselves as 'healthy' irrespective of actual health status and this phenomenon is also found in other chronic health conditions: asthma (Frey 1996) and heart disease (Veldtman et al 2001).

This dual comprehension of CF – a knowledge of the physical components of the disease but an unwillingness to apply them to the self – comes about in part from a parental desire to protect the child from the potentially distressing aspects of CF, what Bluebond-Langner (1991) terms a 'conspiracy of silence' and in part from the reluctance of CF health professionals to include the child in consultations. Parents are used by children as envoys and information brokers; they act as buffers from unpleasant information (Young et al 2003).

### Impact of diagnosis in adulthood

Diagnosis in adulthood, although also often associated with emotional upset, can be different from a parent

receiving diagnosis for their child. This is because the adult will often come to the consultation with thoughts and beliefs about the symptoms that have led to the diagnosis meeting. How the individual's thoughts match the information that is presented, may determine whether the diagnosis is received with acceptance, distress or in some situations relief.

Our knowledge of how patients think about their health has been influenced by a range of theories over the years (Ajzen 1985, Becker 1974, Leventhal et al 1984). Considerable research exploring patients' thoughts about physical health problems suggest that for any condition an individual will have a 'common sense' understanding about the condition, which has been termed an illness representation (Leventhal et al 1984). This is a set of beliefs that revolves around five key themes. These are:

- *Identity* – which describes the symptoms and label that the individual associates with an illness
- *Time-line* – which is related to how long the condition is thought to last for, i.e. whether it is acute, chronic or cyclical
- *Consequences* – which incorporates thoughts about how serious the condition is and the effect that it will have on the lives of both themselves and individuals close to them
- *Control* – including thoughts about the extent that they as an individual can control their illness and thoughts about whether treatment can control the illness
- *Cause* – beliefs relating to what the person attributes the cause of their condition.

These thoughts are a way for individuals to make sense of any symptoms they experience and will influence the behaviours that they conduct; they may be present even before diagnosis. For example, if an individual has chest pain and identifies it as due to indigestion, they may be unlikely to visit a doctor. However, if the pain was interpreted as a heart attack, a very different response might be expected. Such beliefs are important at all stages of illness from diagnosis to the end stages of a condition and are related to outcomes both physical and psychological. For example, the more chronic in nature the condition is perceived to be, the poorer the psychological reaction to the condition. In contrast if the individual perceives that the condition will be controllable or is caused by factors which may be amenable to change, e.g. by changing lifestyle factors such as diet or exercise, their reaction to the condition is generally more

positive (Hagger & Orbell 2003, Moss-Morris et al 2002).

The development of such illness beliefs comes from a range of sources, including:

- general lay information about health, such as might be gained through the media or increasingly the internet
- information from the social environment, including authoritative advice such as from medical personnel
- knowledge of other individuals with similar symptoms
- personal experience which relates to the individual's own previous experience of such symptoms (Leventhal 1984).

The range of sources that feed illness beliefs may explain the variability in reaction to diagnosis of physical health problems and differences in management. Such beliefs must therefore be taken into account at all stages of managing physical illness.

One particularly difficult form of diagnosis in adulthood is that which would normally have been made during childhood, such as late diagnosis of CF. Widerman (2002) reports that CF patients diagnosed as adults can be left feeling confused as often there is uncertainty around diagnosis with perhaps multiple tests before diagnosis is confirmed. Emotional reactions that have been reported include anger, depression, fear and relief (Widerman 2002). For the health care professional working with adults diagnosed with CF over the age of 18, it is important to recognize the significant effect of such a diagnosis and to acknowledge that informational needs may be different from that of a patient diagnosed as a child. Providing time for questions and being alert to the meaning of this for both the patient and their plans for the future, e.g. reproductive health, will be important.

## Post-diagnosis

Diagnosis of a chronic medical condition is only the beginning of a potentially long-term relationship between the patient, parents, doctor and a range of other health care professionals. Fundamental to the relationship is good communication and the building of a strong doctor-patient relationship. Unlike the outmoded traditional approach of paternalistic practice, nowadays the shift in the doctor-patient relationship is from prescription to collaboration (Bodenheimer et al 2002, Kuther 2003). Such a patient-centred approach sees the health care professional and patient as the meeting of two

experts, the patient an expert on the impact of the illness on their individual lives and the doctor an expert on the clinical management of the condition. Evidence of the benefits of a collaborative or patient-centred approach is demonstrated on a range of outcomes including satisfaction, treatment adherence, quality of life and physical health outcomes (Michie et al 2003). Accurate understanding of one's own medical condition correlates with less distress, less confusion, improved relationships with the medical team, better adherence to medication and an improved emotional well-being (Rushforth 1999, Stewart 1995, Veldtman et al 2001).

Collaboration may be more straightforward with the adult patient than the child. How to involve the child in such a collaborative relationship is therefore often something the health care professional may need to guide the parents on. This process can be complex and requires ongoing support. Towle and Godolphin (1999) recommend the following guidelines:

- develop a collaboration with the parents for ongoing information-sharing with the child
- establish the parents' preferences for managing communication
- inform parents of the advantages of including the child as collaborator in their medical treatment
- ensure parents have accurate knowledge
- avoid jargon and technical explanations
- expect that information will be forgotten – ensure repetition at consultations
- when speaking to a child, ask them what they know about a subject first, and expand that knowledge using their own words.

Although targeted at involving children in care, these principles apply equally well when the patient is an adult.

One further aspect of post-diagnosis care is to recognize the social and emotional impact of the diagnosis. In some situations specific support programmes may be implicated. Sawyer and Glazner (2004) have evaluated such a support programme and suggest the essential components of a post-diagnosis support programme should include:

- prompt timing immediately after the diagnosis
- engagement of both parents (if involved)
- clear, comprehensive communication at all stages
- the opportunity for supervised skill development for treatments
- the expertise of the multidisciplinary medical team
- the provision of written material.

## LIVING WITH CARDIORESPIRATORY ILLNESS

Following diagnosis with a cardiac or respiratory condition the adult patient, parent or child will be faced with a number of demands in managing their condition. The challenges inherent in living with a physical illness have been described by Holman & Lorig (2004) as:

- having to manage persistent symptoms without cure
- continuous medication use
- adapting to behavioural changes, e.g. diet/exercise
- undergoing changes to social and work circumstances
- managing emotional distress
- participating in decisions about medical treatment.

Given these significant effects, it is perhaps not surprising that individuals with cardiac or respiratory conditions typically experience reduced quality of life compared with individuals without health conditions (Ekici et al 2006, Garrido et al 2006, Simko & McGinnis 2003). A key objective in working with people with respiratory or cardiac conditions should therefore be helping to improve quality of life while managing these demands.

### Behavioural demands

#### *Adherence*

Compared with 20 or more years ago, both adults and children diagnosed with cardiorespiratory disease are likely to have a far greater life expectancy. Children with conditions such as CF or congenital heart disease now often live into adulthood. However, maintaining relative health in cardiorespiratory illness is not necessarily straightforward and it is increasingly time-consuming. The main reasons for this improved survival are new surgical techniques and in medical respiratory conditions much more aggressive therapy for the chest (including prescription of daily oral and nebulized antibiotics and regular courses of intravenous antibiotics). In addition daily physiotherapy, exercise and adequate nutrition are often essential to maintain good health (Bilton et al 1992, Durie & Pencharz 1989, Valerius et al 1991, Webb & David 1994).

While these treatments offer greater life expectancy, poor adherence to treatment regimen is perhaps the best-documented area of difficulty in managing chronic cardiorespiratory health conditions no matter what age the patient (Geiss et al 1992, Hillyard 2001). Much focus has been placed on how well individuals follow the advice they are given by health professionals which has variously been termed compliance, adherence or concordance. Generally there is good evidence that in

adults, like children, adherence is less than optimal. For example adherence to physiotherapy in CF on a daily basis has been reported to be only 29.5% (Myers & Horn 2006). Other studies (Abbott et al 1994, Conway et al 1996, Shepherd et al 1990) have reported adherence to oral antibiotics to be between 68–93% and exercise to be between 69–75%. Similar findings are found for adherence in other cardiac and respiratory conditions (Hersberger et al 2001). The level of poor adherence to CF treatment, especially with physiotherapy and diet, and to a lesser extent with nebulized therapy (Geiss et al 1992), indicates that patients are making decisions about treatment management based on factors other than purely clinician advice. Patients or parents may deliberately alter treatment regimens according to their own beliefs and personal quality of life assessment, which may not match the aims of treatment held by health professionals. Importantly there is little evidence to suggest that adherence is associated with either the seriousness of the condition or sociodemographic variables such as education levels (Abbott et al 1994, Myers & Horn 2006).

The prescribers of treatment must therefore accept that a degree of non-adherence will be normal. A traditional prescriptive approach will fail to uncover any incompatibility between medical criteria and the patients' criteria for treatment success. Recent recommendations have suggested that a more fruitful approach, in line with collaborative care, is to understand the patient's illness behaviours in terms of self-management (Bodenheimer et al 2002). This encompasses the idea that people manage their condition, including its treatments, in a social and emotional world, and good quality of life is achieved by balancing all of these aspects.

Although adult patients are encouraged to become active collaborators in treatment decision-making, adolescents are not often awarded the same status. A medical relationship with a teenager is more complicated than with an adult above the legal age for consent (Kuther 2003). There are cognitive differences between children and adults in their ability to actively consent to or refuse treatment and this underpins the legal directives.

#### *Improving self-management*

Given that individuals make decisions about the management of their illness based on their priorities within their broader day to day life, the role of the health care professional is to support the individual to make informed decisions and address the patient's identified priorities. Understanding a patient's or parent's treatment beliefs is key to this. Studies suggest that thoughts about the *necessity* of the medication or treatment and

secondly *concerns* about the medication or treatment – e.g. worries about side effects – are particularly important in predicting adherence. In both asthma and cardiac conditions, patients' greater belief in necessity and lower concerns about medication have been shown to be related to greater adherence (Horne & Weinman 1999). Where concerns outweigh beliefs in necessity then adherence will be lower.

In addition, the meaning associated with treatment is important, particularly as an illness progresses and treatments become more demanding. For example, the requirement of an individual to use oxygen is often associated with an adverse reaction by the patient. Frequently this is less to do with the practicalities of oxygen use, but more significantly the representation of this as an indicator that health is deteriorating. At this point understanding what the treatment represents and aiding adjustment to deterioration in health may be an important factor in facilitating use of the treatment.

Another sort of belief that is associated with self-management is self-efficacy. This refers to the confidence an individual has in carrying out a behaviour (Bandura 1986). Self-efficacy can be developed through successful experience, through verbal persuasion such as from health care professionals or through seeing similar others carry out the behaviour. Generally the higher an individual's self-efficacy, the better the self-management behaviours (Zimmerman et al 1996) and the better the physical outcomes such as walking distances and perceptions of dyspnoea (Scherer & Schmieder 1997).

The implications of these findings for practice are that in working with patients or parents to improve self-management their beliefs about the behaviour including worries, concerns and self-efficacy must be elicited. This should supplement traditional approaches of general education and advice giving which, although important, are often insufficient for behaviour change (Kolbe et al 1996). Psychological interventions that target beliefs include cognitive behavioural interventions and recently attention has been given to the value of motivational interviewing as a cognitive behavioural strategy to improve adherence (Miller 1983, Miller & Rollnick 1991). Motivational interviewing is a person-centred intervention which views motivation as a fluctuating state which can be targeted through trained health care professionals facilitating individuals to understand and resolve their ambivalence about behaviour change. It also draws on the concept that individuals may vary in their readiness to change behaviour and has been shown to have use in a range of health care settings (Britt et al 2003).

For children and families, techniques such as a Behavioural Family Systems approach (Robin & Foster

1989) lends itself to this sort of problem as it combines the behavioural techniques of skills training with a systemic focus on structural problems in the family, such as weak parental coalitions and negative belief systems. The approach also allows for the alterations of prescribed treatment. The intervention has been evaluated for families with an adolescent with CF (Quittner et al 2000).

### *Behavioural challenges in childhood*

Although the above issues apply to children and adolescents as well as adults, additional behavioural challenges can be seen in childhood as managing treatment demand is mixed with the normal challenges of raising a child. Levels of parental stress, as measured by the Parenting Stress Index (PSI) (Abidin 1986), have been found to positively correlate with reported child behaviour difficulties, as measured by the Child Behaviour Checklist (CBCL) (Achenbach 1992), but not to correlate with severity of illness, number of hospitalizations or time taken for treatment (Simmons et al 1993). The daily demands of childrearing become a major strain especially around 2 years of age when the child begins to assert autonomy. Oppositional behaviour around treatment can be a major difficulty. As observed at mealtimes, parents inadvertently attend to non-compliant behaviours, so increasing perceived behaviour problems and level of stress. When parents face daily challenges to their authority they lose confidence and become coerced into withdrawing their commands for compliance to any instruction whether or not connected with delivering treatment (Patterson 1984). Behaviour therapy, such as behavioural contracting, parent management training and modelling, has been found to be empirically supported as an effective intervention for use with children and parents (Weisz et al 1995). Parent management training, in particular, is advantageous for the medical team as it can be standardized and implemented from a manual by non-psychologists (Kendall & Chambless 1998, Kendall et al 1998).

### *Managing well siblings*

Although parents are expected to administer their child's medical treatment, this can be time-consuming, disruptive to the family routine and cause parent-child conflict. The parents' reaction to illness can greatly affect all children in the family (Bluebond-Langner 1996). In many cases the administration of medical treatment is incorporated into the daily routine without great difficulty and there is little differentiation between the sick child and other healthy siblings. In some families, however, this is not achieved. It has been documented that mothers differentially respond to their well children and those with CF (Quittner & Opipari 1994). The

well child may well feel bereft of maternal attention and young children will be unable to rationalize this difference. Well siblings may discover behaviours that guarantee a response from parents as a means of correcting the perceived deficit. Generally, these behaviours will be negative (Dunn & Munn 1986).

Risk factors for the development of poor sibling relationships have been identified (Foster et al 1998):

- the differential responding of parents between well children and those who are unwell
- the exclusion of the well child from information about the illness
- limitations of family activity without due explanation
- poor communication about the medical condition with all family members.

Parents can be informed of these potential risks and assessment of well sibling behaviours can be incorporated into a clinic review.

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### Social and work demands

#### *Social and peer relationships*

Although for the health care professional helping patients follow treatments may be a key priority, for the child or adult this treatment must occur within their social world. Qualitative research indicates that one of the most pervasive emotional difficulties facing the school age child with a chronic medical condition is a feeling of difference compared with peers (Angst 2001, Christian & D'Auria 1997). Children will go to great lengths to minimize observable differences between themselves and their peers, and this puts them at risk from failing to conduct necessary treatments.

Strong peer relationships (with children without a medical condition) have been found to be a protective factor from social competence problems (Eiser 1993). For all children, peer relationships provide the arena for the development of social skills and a positive self-concept (Hartup 1983). Children with CF tend to avoid discussion of their illness with peers unless forced and this may restrict the opportunity to have their diagnosis accepted by friends (Zeltzer et al 1980). Again this is a question of managing the balance between accepting the imposition of a chronic illness while trying to make life as normal and routine as possible. School age children can be helped to include their friends in knowledge about their condition and this is more likely to sustain and strengthen a relationship than, as is often feared, result in rejection. Friends can help the school age child with CF to incorporate CF into their self-image and learn to live with a chronic illness (Christian & D'Auria 1997). The importance of school attendance is obvious

and the multidisciplinary team needs to enquire about absence rates and ensure that parents are promoting school attendance.

In adults again social relationships are key, and there is now considerable evidence to suggest that an individual's social context and particularly the support the patient or parent receives from their social network can significantly affect adjustment to chronic illness (McNally & Newman 1999). In general the important factor is not necessarily how large the social network is, but how satisfied the individual is with their relationships (DiMatteo 2004). This may reflect the fact that although a social network may be present, if interactions are negative or unhelpful then support will not be received from the network, for example conflict within a relationship has been shown to be associated with poorer health outcomes (Smith & Ruiz 2002).

The illness itself can also put considerable strain on relationships or act as barriers to developing relationships. For example, adult patients with CF may have worries about entering into friendships or sexual relationships because of concern that others may not be able to cope with their illness. The possibility of not being able to have children may also be of concern within a relationship. Evidence suggests however that although rates of marriage may be lower than in individuals without CF it is still common with up to 45% of adults reported to be, or have been, married (Yankaskas & Fernald 1999). Again a difficulty that can arise for adults, as with children, is when patients avoid telling friends and family about their condition. Although this may be manageable at early stages of an illness, as health deteriorates and treatment requirements increase, this can become increasingly difficult. Interventions targeted at communication and relationship issues can be helpful although an individual's autonomy in making such decisions must also be respected. Interventions directed at family members have also been shown to be useful (Martire et al 2004). These may be focused either directly at the needs of the family member or at helping family members provide support to the patient.

#### *Employment*

Living with a cardiac or respiratory condition can also have significant implications for employment. As illness progresses the individual may become too physically unwell to work full-time and may need to work fewer hours, change their line of work or ultimately give up work. The implications of this can be both financial and social. From a financial perspective loss of earnings can place significant burden on a family. Although welfare benefits are available, these may not equate with previous earnings. In addition some individuals may associate the receipt of benefits with stigma. Helping

individuals overcome the psychological barrier to receiving benefits is important to help individuals maintain as good a quality of life as possible.

### Role changes

In understanding the social impact of illness it is important to understand the concept of roles and the changes that can occur when diagnosed with a cardiac or respiratory condition, or when illness deteriorates. Most individuals will fulfil a number of roles at any point in their life, e.g. as parent, child, carer, financial provider. When diagnosed with a physical illness or as an illness progresses, these roles can be challenged due to the physical limitations the illness exerts. For example, adults who worked to provide an income for their family may feel they have lost their role of provider if they have to give up work. Similarly the individual who cared for the family but then – due to illness – requires care, may find this reversal of role difficult. Changes in roles can lead individuals to feel their identity has been challenged and can result in negative emotions if not managed well. It is therefore important to understand the different roles that are challenged by the individual's illness and work with patients to both accept the loss and to help identify new roles that may be undertaken. In addition, helping individuals to see that some roles remain the same regardless of illness, for example friend, partner, etc., can be important in retaining well-being.

Although role changes are often thought of in terms of those undergone by the patient, significant role changes may also be experienced by those close to the patient. For example, the partner or spouse of an ill individual may have to take up employment to support the family or conversely may feel they are unquestioningly forced into a caring role. Although for many people this is done without resentment, in some instances it may cause difficulties and it is important that these individuals are provided with sufficient support.

tional impact of their health condition. Theoretical approaches to stress and coping such as that used by Lazarus and Folkman (1984) talk in terms of people making an assessment of the demands a situation presents (primary appraisal) and then the resources they have to meet these demands (secondary appraisal). Where demand outstrips resources, the situation is said to be perceived as stressful and actions are then needed to manage the situation. Coping refers to those actions taken to manage the stress. In cardiorespiratory illness people have many demands placed on them and hence it is not surprising people find the situation stressful. For example, parents of recently diagnosed children and preschoolers report higher levels of parenting stress and depressive symptoms than normal controls (Quittner et al 1992, Simmons et al 1993). Parent stress levels have been found to have a negative effect on the physical health of a child. Problems with family, friends, school and finances correlated with lower pulmonary function and lower height/weight indices over a 15-month prospective study (Finkelstein et al 1992).

In coping with the stress of illness people use a wide range of strategies. Table 7.1 shows a range of different strategies. The table has been split into two columns: active, problem-focused coping strategies versus more passive, avoidant coping strategies. Research in a range of cardiac and respiratory conditions tends to suggest that more problem-focused coping is associated with better psychological adjustment, while avoidant strategies are less helpful. For example, Abbott et al (2001) reported avoidant strategies to be associated with poorer adherence to physiotherapy and enzyme regimens; Barton et al (2003) report emotion-focused coping to be associated with poorer adherence, more hospital admissions and more frequent asthma attacks in patients with asthma; and Hesselink et al (2004) found emotional coping style to be associated with poorer health-related quality of life in both asthma and COPD. These studies must be treated with caution, however, as the

## EMOTIONAL IMPACT OF A MEDICAL ILLNESS

Given the areas of life that can be affected by illness, it is perhaps not surprising that cardiac and respiratory conditions have an impact on psychological well-being in both adults and children. These effects can lead to either general stress and difficulty coping or more formal diagnoses of anxiety or depression.

### Stress and coping

The term coping has often been used to refer to how well individuals manage both the physical and emo-

**Table 7.1** Summary of different coping strategies

Active/problem-focused coping	Passive/avoidant coping
Seeking information	Withdrawal
Problem solving	Wishful thinking
Cognitive reinterpretation	Avoidance
Seeking emotional support	Denial

usefulness of a coping strategy will very often be dependent on the particular situation.

One particular coping strategy that has variously been described as both helpful and unhelpful is denial. Denial has been described as when an individual does not acknowledge the reality of a situation and acts as if the situation does not exist. Particularly in the field of cancer, denial has been said to help an individual maintain hope and provide time for adjustment to the reality of their situation (Morley 1997). However, others have argued that it can provide barriers to communication (Fallowfield et al 2002), can prevent uptake of beneficial treatments and can act as a barrier to acceptance of the health condition. In working with denial it is important to understand exactly what is behind this and the purpose it holds for the individual. Given the complexity of this it may often be most appropriate to refer to a specialist trained in this area, such as a psychologist. It should be pointed out as well that denial may be less frequent than typically believed by the health care professional and may actually reflect that the patient has simply not 'heard' or understood information that has been told to him about his condition. This may particularly be the case where individuals have been given bad news in a way that has not accounted for the time required to process this information.

If an individual is seen to be having difficulty coping it may be appropriate to refer him to a trained member of the team who can work on positive coping strategies. For example, individuals may be taught problem-solving techniques, can be taught how to manage emotions through exercises such as expressive writing, can be taught social skills and communication which facilitate increasing social support and may be aided in cognitive re-interpretation of symptoms.

## Anxiety

Anxiety and panic are common in both respiratory and cardiac conditions, with prevalence typically higher than in individuals without physical health problems (Brenes 2003, Goodwin et al 2004, MacMahon & Lip 2002). The causal relationship between anxiety and particularly respiratory conditions is often not clear: for example, in some instances the experience of breathlessness may precipitate anxiety, whereas in other instances anxiety precipitates breathlessness. In asthma for example there is some evidence that anxiety may precipitate an attack (Lehrer 1998).

Correct diagnosis of anxiety is important for treatment. However, the similarity of the symptoms of anxiety, such as increased breathing and heart rate, sweating, etc., with physiological characteristics of disease can complicate this. In diagnosing anxiety it is

therefore important to also focus on the thoughts and feelings associated with anxiety such as feelings of nervousness or dread.

Although anxiety can be related to a range of factors in respiratory and cardiac conditions it is commonly precipitated by increased exertion and the fear that activity will cause breathlessness. If individuals fear that they cannot manage breathlessness they may then avoid activity, and this can engender a vicious cycle whereby through lack of activity the person becomes physically deconditioned and hence more easily breathless on exertion, which reinforces the sense of panic and anxiety (Fig. 7.1).

In managing anxiety a range of interventions may be useful. Explanation of the cycle of anxiety and reduced functioning can be beneficial as can education to help individuals differentiate symptoms due to anxiety versus those caused by their physical illness. Relaxation and distraction techniques exercises have also been shown to be effective in some respiratory conditions (Stetter & Kupper 2002). Attendance at cardiac or pulmonary rehabilitation programmes where individuals have the opportunity to build confidence in exercising can also be helpful. Further, work with individuals to elicit their worries or concerns are important. Where anxiety is chronic or interfering with daily functioning, it may be necessary to refer the individual for specialist psychological input where techniques such as cognitive behaviour therapy have been shown to be of benefit (NICE Guidance 2004).

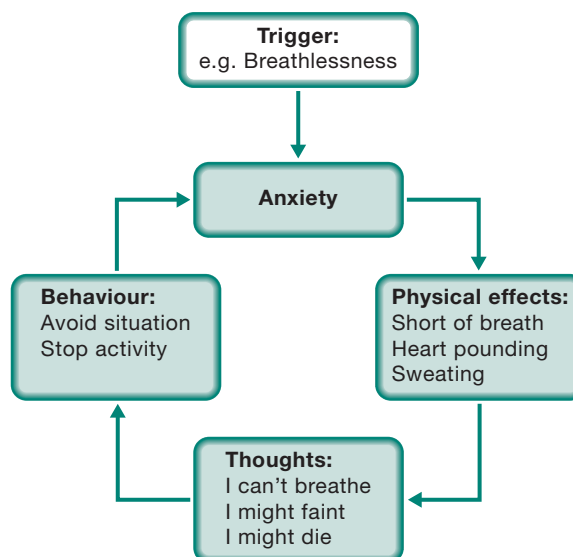


Figure 7.1 Relationship between breathlessness and anxiety.

## Procedure-related distress

One area where anxiety commonly occurs is in relation to procedures. This is true for both adults and children. Treatments for procedure-related distress and phobia have developed over recent years. Initially attention was focused on hospital education programmes (Harbeck-Weber & McKee 1995), which typically provided information specifically on the procedures to be encountered using modelling, photographs or video. These programmes were found to be particularly effective for patients who had no previous experience of hospitals (Melamed 1992). Patients undergoing painful procedures, however, require more specific coping strategies to help reduce distress. The predominant treatment involves cognitive behaviour modification and there has been a high degree of consistency in the type of treatments used across medical specialties:

*Deep breathing exercises (Jay et al 1985).* These are aimed at helping the patient to actively learn mastery over pain and anxiety rather than becoming passive and submissive. Breathing exercises help the patient to divert attention from the procedure and to relax. The procedure is best taught using modelling along with an instruction to pretend to be, for example, a balloon – to slowly breathe in to fill the balloon, then slowly breathe out to make the air leak out again.

*Distraction (Blount et al 1994).* This is found to work best in the early, anticipatory phase and can be incorporated with the breathing exercise, for example using a party blower. Distraction techniques can be any number of items dependent on the patient's age and interest. Younger children can be distracted by moving objects and toys, older children and adults use counting forwards and backwards as a means of occupying the mind on an alternative activity.

*Guided imagery (Lazarus and Abramovitz 1962).* Patients are first asked about their favourite superhero, cartoon character, role model or film star. A story is then developed that includes the character using their powerful, special skills to help the child cope with the medical procedure. Older children and adults can produce their own fantasy image that is incompatible with pain, for example, a favourite place. The guided imagery is often used in conjunction with breathing exercises and is worked out before the procedure. The health professional or parent then prompts the patient to use their imagery during the procedure.

*Filmed modelling (Jay et al 1985).* A film is made of a patient with the same medical condition (or in some cases a model) undergoing a painful procedure. The patient describes his/her thoughts and feelings and

how they are using coping strategies to reduce their worries. The film includes the health professional guiding the patient through the procedures.

*Reinforcement/incentive (Manne et al 1990).* The patient rehearses the events of the procedure beforehand, including the stages of the procedure, each coping strategy and how they might feel; they then undergo the procedure using their techniques of pain management. The patient receives an agreed reward at the end of the procedure, usually a trophy or certificate, though in the case of adults the satisfaction of undergoing the treatment successfully can be reward in itself.

*Active coaching and positive self-statements (Powers et al 1993).* This is particularly useful with children but can be adapted for adults. The child pretends to be the doctor and to implement the procedure on a doll. The child coaches the doll to use breathing exercise and distraction. At each stage positive coping statements are made as observations of the doll's progress. Parents are involved to describe and promote coping skills used by the doll. This process is conducted for several sessions before the actual procedure and parents are then used to help coach the child at the event.

Packages of cognitive behavioural interventions for pain management with children have been found to be superior to diazepam, watching cartoons prior to the procedure or general anaesthesia (Dalquist et al 1985, Jay et al 1987, Kazak et al 1996). The use of cognitive behavioural strategies is efficacious but time-consuming and impractical in a busy clinic setting. These therapeutic techniques need to be conducted outside the clinic to treat severe cases. Some of the simpler methods of distraction or a combination of distraction with pharmacologic approaches may be equally as good as a series of cognitive behaviour desensitization training sessions for some procedural anxiety (Cohen et al 1997).

## Depression

Like anxiety, depression is common in individuals with chronic illness. In heart failure prevalence rates have been estimated to range from 13% to 77%, depending on how depression is assessed (Thomas et al 2003). However, if a major depressive episode is the criterion it is estimated that 20% of individuals hospitalized with heart failure will have depression. High prevalence rates are also common in respiratory conditions (Goodwin et al 2004). In a major study looking at long-term risk for depressive symptoms following diagnosis from a range of medical conditions, individuals diagnosed with respiratory and cardiac disease were at higher risk 2 years after initial diagnosis than those

diagnosed with a number of other conditions including diabetes, hypertension, stroke or arthritis (Polsky et al 2005).

Depression has been shown to be associated with significantly poorer physical outcomes than in individuals without depression. For example, in patients with coronary heart disease depression is associated with poorer adherence (Gehi et al 2005), in heart disease with higher mortality (Murberg et al 1999) and reduced prognosis (Rozanski 1999), and in COPD with increased morbidity (Yohannes et al 2003).

Although detection of depression is essential for adequate management it is often underdetected, in part because physical symptoms of depression such as weight loss, loss of energy and disrupted sleep patterns overlap with symptoms caused by the illness. While moods may fluctuate with changes in health, and depression may be prevalent, this does not mean it should simply be considered normal or that it should be ignored (Rosenfeld et al 2005). Diagnosis can be aided by looking at the individual's thoughts. With depression these are typically negative with view to self, the world and the future. There may also be evidence of feelings of guilt, hopelessness and loss of interest in previously enjoyed activities, and withdrawal from social contexts and are all associated with depression. Unfortunately the physical limitations that cardiac and respiratory conditions place on individuals can trigger a vicious cycle of withdrawal from activity, negative evaluations of life, deepening depression and further withdrawal. Where depression is mild, rehabilitation programmes that incorporate mood and adjustment have been shown to reduce emotional distress and subsequent morbidity and mortality. This is true for both cardiac (Denollet & Brutsaert 2001) and pulmonary rehabilitation programmes (Alexopoulos et al 2006). Alternatively, if depression is more severe, referral to a psychologist may be beneficial. Work may then focus on recognizing the association between limitations from the illness and mood state, managing changes in activity levels, scheduling pleasurable events, addressing negative thoughts and focusing on coping strategies to aid adjustment to the current physical state. For individuals where depression is severe and a more cognitive approach is not appropriate, antidepressant medication may be beneficial although interaction with any current medications for the cardiac or respiratory condition should be taken into account.

### Cognitive functioning

In managing an individual with cardiac or respiratory illness it is important to also consider cognitive functioning. Cardiac and respiratory conditions can them-

selves influence cognitive functioning through, for example, hypoxia, which is common in cardiac or respiratory disease (Bennett et al 2005). Cognitive functions that may be affected are attention, concentration, memory, academic progress, communication and decision-making. If concern over an individual's cognitive functioning is apparent, specialized assessment should be sought and with children, liaison with the local educational authority or communication with the school special needs coordinator. This is particularly important if an individual is to undergo procedures where informed consent must be obtained or where complex decisions such as whether to be placed on a transplant waiting list are being considered.

### TRANSITIONAL CARE

One specific form of role change is that undergone by the adolescent in transition between being a dependent child and an independent adult. This is a particularly important period and its recognition within cardiorespiratory services is increasing. Well-established transitional care initiatives have come from CF services and these will be used as an example here. The issues identified within CF are directly applicable to a range of services where medical knowledge and expertise originates in the paediatric setting.

### Adolescent issues

The adolescent stage of development is perhaps one of the most challenging for children and parents to negotiate; when the teenager also has a life-threatening chronic illness the potential for even greater problems is enormous. The most significant emotional development at this stage is to achieve complete autonomy from their parents as childrearsers. There are similarities with the preschool years in that the parents must provide a secure base from which the adolescent can explore the world. Parents of healthy adolescents find this stage particularly challenging (Birch 1996) and those with adolescents with cardiac or respiratory conditions have larger battles to contend with. The cognitive developments that occur at this stage of childhood enable more abstract thought, facilitating analysis and synthesis of ideas and holding mature representations of the world (Piaget 1952). The adolescent is no longer an accepting recipient of the opinions of his elders, but will think for himself. This developmental process necessitates challenging and rejecting previously held beliefs as the adolescent becomes an adult. Of course, that first major target for rejection is the opinions of parents. It is an indication that the parents are providing a safe base if the adolescent can rebel. Many parents see this as a

failure of their parenting, but it is quite the opposite (Wolman et al 1994).

Adolescents with chronic illness must undergo the same developmental tasks as their healthy peers: physical and sexual growth, personal individuation, intimate relationships, finding a comfortable social group, educational goals and preparation for an occupation. The medical progress and continued optimism for treatments for CF, in particular, mean that it is a different disease from that of a few years ago; the emotional and behavioural preparation of adolescents and young adults has not kept pace (Mullins et al 1994). There is a paucity of guidance for psychosocial support of adolescents with CF relative to that available for younger age groups (Drotar 1995).

Many adolescents with CF have delayed puberty and are smaller and thinner than their peers. Adequate nutrition becomes a greater problem and there is increasing evidence that adolescents are at greater risk than their healthy peers for developing eating disturbance (Shearer & Bryon 2004), a negative body image and poor self-esteem (Bywater 1981, Shearer & Bryon 2004). Concomitant with a delayed puberty are reported delays in developing a sexual identity and forming intimate relationships, especially in girls (Orr et al 1984, Sawyer et al 1995).

Adolescents with CF may find the process of separation and individuation more challenging than their healthy peers, as the parent-child relationships established following diagnosis tend to be overprotective and enmeshed (Goldberg et al 1995, Matas et al 1978). Parents of adolescents with CF may be more restrictive of their adolescent's social independence than they would be otherwise. Consequently, adolescents with CF may be less well prepared for independent adult life than their healthy peers in terms of moving from home, seeking financial independence and managing their own health. The potential conflict between natural maturation and restriction imposed by parents and CF treatment could well spark a rebellion, the risk-taking behaviour that illustrates this stage of development (Jessor 1991).

A combination of a perceived unreceptive social group, parental overprotection, physical differences, demands of daily treatment and personality factors will affect adjustment during this stage of development. Studies of the prevalence of risk-taking behaviours in adolescents with chronic illness find, however, that they are less likely to engage in such behaviours than their healthy peers (Alderman et al 1995, Frey et al 1997) and more likely to engage in injury-prevention (Britto et al 1997). Adolescents with CF first attempt smoking, alcohol and sexual intercourse later than their age- and race-matched controls and are less likely to have unprotected sex (Britto et al 1997). In summary, adolescents

with cardiorespiratory conditions are not at greater risk for increased teenage rebellion than their healthy peers; perhaps the scrutiny of their parents and the medical teams, which often include a mental health professional, prevent this. It is clear though that they engage in the same sort of risk-taking behaviours as their peers and these behaviours may have great health risks, particularly smoking and unplanned pregnancy. Paediatric and adult medical teams must be equipped to discuss these potential health risks in confidence with their adolescent patients.

### Implications for health care teams

Paediatric teams typically communicate via parents about the child patient; the philosophy of care is prescriptive, nurturing and protective. Adult health care systems focus contact on the patient with a philosophy that is collaborative and empowering. Expectations are for shared decision-making for treatment with all the implied independent responsibility (Rosen 1995). Clearly there is a need to bridge the gap between the paediatric system and the adult one. A process of transition needs to begin in the paediatric setting to prepare the adolescent with skills to negotiate the adult system and then to continue in the adult setting to facilitate gradual adaptation.

A simple administrative transfer of care from one doctor to another is an inadequate method for patients with a chronic illness who have received multidisciplinary care in the paediatric setting. A transitional method that emphasizes a guided educational and therapeutic process is required. Acceptance of the need for transition has not resulted in consistent development of services and there are wide variations in practice (Viner 1999).

Most paediatric CF teams will be aware of the developmental challenges that adolescents bring and their need for resources that are frequently unavailable within a paediatric setting (Sawyer et al 1997). Young people with CF have drives to leave home, learn to live with a partner, start an occupation, manage a home, find a congenial social group and assume civic responsibility, plan for a family and/or cope with infertility. It is essential for health care providers to have a working knowledge of the emotional impact that CF will have on the lifestyle and expectations of young people.

### Barriers to effective transition

Although there is an acceptance that transitional programmes should be part of the paediatric service resulting in the eventual transfer of care to an adult setting, one of the most frequent barriers to transition comes from the paediatricians themselves, who refuse to hand

over their adult patients. This may stem from a long-term attachment to the patient and family, a lack of confidence in the medical skills of the adult physician in adequately caring for the medical condition, or fears that numbers in the paediatric clinic will drastically reduce (Schidlow & Fiel 1990).

Parents and the adolescent patient may also hinder the transition process. Transition is a difficult process that can cause a great deal of stress; to leave trusted health professionals with whom strong relationships have been formed, and face the prospect of the potentially anxiety-provoking task of forming new relationships is quite aversive. Parents may fear that their child will receive inadequate care. Adolescents themselves may fear that the adult services take them one step closer to death. The adult service will undoubtedly have differences in delivery of care that may cause concern, particularly in advocating the withdrawal of parents from the medical consultations (Bryon & Madge 2001). Clearly, there is little incentive to make the change.

## 7

### Models of transition

Policies of transition are developing, but as yet there is no consistency and most are constrained by local resources with little evidence on programme efficacy (Sawyer et al 1997). The first model is one where little or no transition occurs; either the patient continues to receive their care from the paediatrician or is simply transferred to an adult pulmonary/cardiac clinic rather than a specialist team. Such a model is inadvisable and may result in anxiety and poor medical management. An adult multidisciplinary team is essential to ensure the needs of the adult CF patient are met and the relationship between patient and health professional has a good start (Mahadeva et al 1998).

The second model currently in practice is the adolescent clinic. In this model, patients between 14 and 19 years attend a separate clinic from younger children. The focus is on more adolescent-type issues and the aim is for intermediate preparation before the final move to an adult clinic. Adolescent clinics are usually located at the same hospital as the paediatric clinic and run by the same staff. The clinics are organized differently, however, with facilitation of greater autonomy for the patient and confidentiality to discuss psychosocial issues (Viner 2001).

The third model is the transition clinic where care is provided concurrently by paediatricians and adult physicians for patients within the transition age range; this varies between centres but is generally over the age of 14 years. An example is where the adult team visits the paediatric clinic to see adolescents and families jointly with their corresponding health care professionals. The

idea is that the adult team are introduced to patients and families before transfer of care occurs. The patient and family similarly gain knowledge of the adult team and assurance that treatment management will continue along the same lines (Webb et al 2001).

Transition is a 'rite of passage' for people with chronic cardiorespiratory conditions who must have access to developmentally appropriate care. Transition is a process that begins in the paediatric service and continues into the adult clinic. Transition policies must become an expected part of the paediatric and adult services (Blum et al 1993).

## DEATH AND DYING

### End stage of life

One of the final challenges for any individual with cardiac or respiratory disease is managing the terminal phase of illness and impending death. It has been theorized that when faced with the certain knowledge of one's end of life, the individual goes through a sequence of reactions (Kubler-Ross 1969). It is now known that this is not an exact series of steps, although many patients find the description of the feelings reassuring. These were described as:

- *Denial* – represented by a lack of acknowledgement of the prognosis
- *Anger* – this may be directed at a range of people or situations or may be turned inwards towards oneself and occurs once the reality of the situation begins to be accepted
- *Bargaining* – often with relation to God
- *Depression* – once bargaining is unsuccessful the patient is said to experience a period of sadness, sometimes to the level of depression
- *Acceptance* – this final stage is said to be where the person accepts the reality and can become at peace with the situation.

In working with people at the end stage of their lives it is important that the health care professional gives the patient, whether adult or child, the space to ask questions and also gives permission to discuss this stage of their illness (see von Gunten et al (2000) for discussion of communication techniques at end of life). In discussing dying with patients it is important to elicit specific fears the individual has; for example, these may be related to how they may die, whether they will experience pain or more existential issues. Only by identifying the individual's unique worries will appropriate intervention be possible.

A common challenge when working with people who are dying is when family members request that the patient is not told of what is happening. This request may be particularly common with relatives of child patients but can occur with adults as well. Evidence suggests, however, that individuals want information about their health status and that this can help both the patient and family avoid uncertainty, maximize control, bring order to chaos and make sense of the illness (Fallowfield et al 2002). In working with families who request the patient is not told it is important to help the family member understand the advantages of telling the patient, such as allowing open communication about worries and concerns, and the risks of not discussing information with the patient: for example, not providing an opportunity to say goodbye.

## Bereavement

Bereavement is the process which an individual goes through when they experience the loss or death of someone they love; grief is the reaction associated with this and mourning the behavioural and emotional reactions to grief (Payne et al 2000). It is important that although bereavement and grief are common across cultures, the form that mourning takes may vary among cultures and differences in behaviour should be understood in terms of cultural norms.

In understanding bereavement, a number of theories and models have been put forward. Stage models similar to that described above by Kubler-Ross have been described; however, they suffer from the same limitations as previously discussed. Another well-known theory by Parkes (1988) has described bereavement as a psychosocial transition. This suggests that everybody has a set of assumptions of how the world and life should be. This is called an internal model or 'schema'. If something occurs which requires us to make changes to our assumptions about the world and these changes are going to be long term and occur over a relatively short period, then the individual is said to undergo a psychosocial transition. Bereavement is one such psychosocial transition, as individuals have to change a number of their assumptions about the other person being around and the subsequent implications. This

requires a period of adjustment and can be a painful process as is experienced in grief. Payne et al (2000) have described a range of reactions to bereavement such as:

- *Physical* – fatigue, disrupted sleeping, changes in appetite, muscular pains, nausea, increased colds and infections
- *Behavioural* – searching, restlessness, crying, social withdrawal, irritability
- *Cognitive* – poor concentration and memory, repetitive thoughts about the deceased, helplessness, hopelessness
- *Emotional* – depression, anxiety, anger, guilt, loneliness.

It is important to recognize that reactions vary among individuals and that there is no correct way to grieve. Explaining this to individuals may help take away anxiety that they are not responding appropriately. Providing the bereaved person with space to talk about his feelings will be helpful. In some instances where the bereaved person has feelings of anger or guilt these may come out as blame, particularly towards the health care professional. Understanding the basis of such expressions and using this to be able to listen and help the bereaved person work through his feelings can be a more helpful approach than taking any accusations to heart and being defensive.

## CONCLUSION

The impact of living with a cardiothoracic illness, whether as a parent or a patient, has been outlined above. Theoretical models and research have expanded the knowledge base such that a thorough understanding of the psychological and emotional correlates of living with disease is obtained. Physical health status can be affected by the individual's emotional well-being, directly via anxiety or depressive reactions and indirectly in terms of coping styles and perceptions of health status. This chapter has aimed to outline the emotional and psychological components of cardiac and respiratory disease, to aid the multidisciplinary health professionals in their relationship with their patients.

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