Common psychological challenges for patients with newly acquired disability


Summary

A patient’s attitude to a newly acquired disability can often be the determining factor in successful rehabilitation. This attitude is determined by his or her perceived ability to manage symptoms, deal with hospital procedures, form and maintain relationships and manage his or her feelings about the disability. Because of this complexity, psychological aspects of patient rehabilitation are often regarded as vague and difficult to negotiate. This article describes seven common psychological challenges that patients experience with a newly acquired disability or during recovery from major illness (Moos and Schaefer 1984). Strategies are outlined to assist patients to come to terms with their disability and to cope more effectively during rehabilitation.

HERE IS a wealth of studies examining what disability means in relation to coping, crises and health (Steptoe and Wardle 1994). Medical approaches have tended to neglect the social and psychological aspects of disability. Impairments were often viewed exclusively in negative terms with loss being experienced until some form of adjustment or acceptance was achieved. This is not surprising considering the everyday need for practical solutions (Siegert and Taylor 2004). However, in situations where patients feel empowered their ability to cope is readily seen (Department of Health (DH) 2001).

This article discusses Moos and Schaefer’s (1986) framework and highlights the implications for health professionals involved in patient rehabilitation. Moos and Schaefer (1984) proposed a useful framework to describe the recovery and coping of individuals with a disability. This is a theoretical framework which was informed by crisis theory, cognitive behaviourism and coping processes. They used a general concept of health crisis ‘which produced a vivid confrontation with a severe physical illness or injury, prolonged treatment and uncertainty and intense personal strain’. Moos and Schaefer (1984) described the process as a series of seven challenges that the person with a newly acquired physical disability had to overcome:

- Learning to detect and manage symptoms.
- Dealing with hospital procedures.
- Developing appropriate relationships with staff.
- Managing upsetting feelings while maintaining hope for the future.
- Preserving a competent self-image despite dependency.
- Maintaining relationships with family and friends to provide support.
- Preparing for an uncertain future.

Since these challenges represent key elements in the coping process, how patients meet these challenges will determine the quality of success with rehabilitation.

Crisis theory is concerned with how people cope with life transitions (Caplan 1964). It has provided a framework for preventive mental health and reactions to physical illness or injury. Like physiological homeostasis, people also have a need for psychological homeostasis. A physical illness, however, challenges this usual state of equilibrium and

Key words

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- Psychology
- Rehabilitation

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characteristic coping patterns are used in an attempt to restore balance.

According to crisis theory, an individual is much more receptive to outside influence during times of challenge and disequilibrium, offering health and social care workers an opportunity to make an impact on people’s lives. A crisis will be a turning point from which adaptive or maladaptive behaviour may develop, depending on the nature of the coping response. This is why careful consideration should be given to selecting any form of action in a crisis.

Cognitive behaviourism is the process of regarding one’s thoughts as a reflection of one’s behaviour (White 2001). Just as a person’s behaviour can be encouraged or discouraged by appropriate reward or lack of it, so one’s thoughts can also be changed by appropriate consequences. This includes using other thoughts to confirm or refute these thoughts, or other behaviour to make thoughts stronger by giving them an end result in reality.

Moos and Schaefer (1984) described the challenges and reviewed coping responses, but offered few practical guidelines for health professionals wishing to use the framework to help patients during rehabilitation. Coping mechanisms were conceptualised as being of three types:

- Appraisal-focused coping – for example, redefining the meaning of the crisis in one’s mind.
- Problem-focused coping – for example, taking action by seeking information or dealing directly with the problem.
- Emotion-focused coping – for example, reacting emotionally to a situation.

They suggested that caregivers could recognised and respond to the adaptive efforts that patients make by understanding their own reactions to acute health crises. Health professionals can then provide information, give emotional support to help patients cope by finding meaning in the event itself; comparing him or herself to able-bodied others who do not have the same disability; looking for support, perhaps by joining self-help groups or through friendship; making appropriate consequences. This includes using other thoughts to confirm or refute these thoughts, or other behaviour to make thoughts stronger by giving them an end result in reality.

- Causal – why does this kind of thing happen?
- Selective incidence – why does it happen to me?
- Responsibility – who is responsible?

Patients who had a stroke and were able to find a causal meaning were less depressed than those who had a similar level of physical disability (Thompson 1991). If meaning could be found, particularly a cause, then the event might seem avoidable or within the patient’s power to control. Finding meaning put the experience into perspective and led to a better patient outcome. However, asking the question ‘Why me?’ is associated with a worse outcome because it reflects a view of the patient as a victim. The patient is unfairly comparing him or herself to able-bodied others who have not experienced the same trauma. A more positive enhancement of self-esteem is often accomplished by making favourable comparisons with others less fortunate (van der Zee et al 2000).

Learning to detect and manage symptoms

The patient needs to develop an understanding of the illness and related symptoms to be fully involved in the rehabilitation process. Health professionals, including nurses and medical staff, are intimately involved in this process and will provide information for patients on the illness, the signs and symptoms, whether it can be cured, how it can be managed and the effects it will have on the patient’s life and the lives of family members. Patients need to know how best to manage their symptoms and adapt accordingly. Patients can be taught new dietary habits, patterns of mobility and ways of performing bodily functions, but it may be more difficult for them to find meaning in why the illness or injury occurred.

This concept has proven crucial to successful rehabilitation (Scharloo et al 1998, Whitmarsh et al 2003). For example, Scharloo et al (1998) found that a belief in controllability or curability of the disease was significantly related to a good outcome, whereas a strong illness identity and passive coping were associated with a poor outcome. Whitmarsh et al (2003) found that illness representations and coping strategies could predict which patients would attend or not attend a cardiac rehabilitation programme.

Some patients react to the sudden knowledge that they have a newly acquired disability by redefining the situation that threatens their usual concept of health (Maes et al 1996). They may do this by finding meaning in the event itself, comparing themselves with others less fortunate, focusing on personal attributes that make them appear exceptionally brave or well-adjusted in their own mind; creating hypothetical situations which could have been worse; or by perceiving the event as fostering their self-development and making them a better person.

Coping mechanisms may involve focusing on the problem and seeking information about the disability; looking for support, perhaps by joining self-help groups or through friendship; making compromises; or pursuing alternative goals (Buunk and Ybema 1995).

Thompson (1991) described three attributions that patients experienced in reaction to having a stroke:
Responsibility attributions may be beneficial, depending on who is thought to be responsible. Blaming others can absolve guilt, but leads to less control. If individuals find that they are to blame, they might feel more traumatised, because blame condemns the self and leads to lower self-esteem. Patients can resolve this by accepting responsibility but not blame. Patients can accept the possibility that they can change; this provides an opportunity to live life in a positive way.

**Helping patients to manage symptoms** This is an important aspect of rehabilitation. Health professionals should ask questions to try to determine what patients think is wrong with them, and whether the symptoms can be cured or managed. Checks should be made to ensure that patients understand the cause of their symptoms. They should be kept informed of their treatments and any changes in their condition so that they can take an active role in, and share responsibility for, their rehabilitation. Patients should also be aware that they are not the only ones experiencing such difficulties.

The desired outcome is that patients understand how their situation arose and learn to manage their condition to the best of their ability.

**Dealing with hospital procedures**

Post-surgical rehabilitation may be helped or hindered by the patient's view (Duits et al 1997). For example, Sugarbaker et al (1982) suggest that quality of life is better for patients after an amputation compared with those who experience ongoing pain and unsuccessful attempts at limb salvage. They argue that amputation should be viewed as reconstruction not mutilation. Effective planning before a surgical procedure can make recovery easier for patients and their relatives. Consideration should be given to those whose lives will be affected by the procedure and what practical and emotional support they will need. However, it is usually not possible to prepare patients for a stroke, fall, accident or sudden disability. Assessment of the patient's point of view becomes an essential first step in determining the best way to help them to become active participants in rehabilitation programmes.

Three factors have been found to be associated with successful rehabilitation (Norman and Bennett 1996). They are:

- **Internal locus of control** – a personality variable.
- **Health value** – how worthwhile the patient believes the end goal to be.
- **Self-efficacy** – the extent to which the patient believes he or she is capable of performing the discrete rehabilitation skills required.

**Locus of control** This personality variable is probably learnt in childhood (Zarit et al 2003). People who have an external locus of control tend to rely on others to solve their problems. They believe that their outcome is determined by powerful others or is due to chance. People with an internal locus of control believe that they are responsible for their own outcome and that this will turn out to be positive if they keep trying. Health professionals can assess locus of control by asking patients if they believe that it is up to them to succeed or if they believe that they should rely on others. Practitioners can also ask the patient whether he or she attributes success in rehabilitation to his or her determination or to external factors.

Even if the illness cannot be cured, some feeling of perceived control is vital to allow the person to cope. Perceived control over treatment and choice also enhances a sense of mastery over the disease even if it is very disabling, for example, Parkinson's disease (MacCarthy and Brown 1989).

**Health value** Patients often have to choose between new ‘healthy’ and old ‘unhealthy’ or mal-adaptive behaviour during a rehabilitation programme. Health value measures the value patients place on their health and therefore the likelihood that they will agree with the goal of treatment. Patients who have a low health value will not be co-operative with rehabilitation because it is not one of their goals. Attempts to force the issue may create antagonism (Steptoe and Wardle 2001).

How much patients value their health can be assessed by asking them to compare the importance of health with other virtues like everlasting salvation, financial security, close relationships and world peace (Norman and Bennett 1996).

**Self-efficacy** This refers to the extent to which patients believe they are capable of performing a certain task. This could include any new movement or manoeuvre that they are being taught that could form part of an activity of daily living. Self-efficacy, or the patient's confidence in his or her ability, can influence the adoption of healthy behaviour patterns, maintain those patterns in the face of difficulty and reduce the body's physiological responses to stress (Maddux 2002).

Self-efficacy can be assessed by directly asking patients how difficult they consider a specific rehabilitation activity to be. For example, consider that the target skill is learning to transfer from bed to chair safely and independently. Ask the patient to rate how confident he or she is in his or her ability to perform these transfers each day during the next week. A percentage scale can be used, where 100 is fully confident, 50 is partly confident and 0 is not confident, and the numbers in between represent different degrees of confidence (Resnick and Jenkins 2000).

**Helping patients to deal with hospital procedures** It is useful to assess the patient's locus of control, health value and self-efficacy to adjust rehabilitation to the patient's circumstances. An internal locus of control can be encouraged, the
value that patients place on their health can be explored, and self-efficacy can be maximised.

Conditions that could favour an internal locus of control should be encouraged. For example, encourage patients to explore alternative ways of performing an activity and offer support and guidance if they fail. The concept that should be engendered is that success on any given activity is due to the patient’s own skills rather than chance or excessive help from others.

Self-efficacy and confidence can be increased by carefully regulating the difficulty of the activity to meet the needs of each individual patient, thus ensuring that optimal functioning in rehabilitation is achieved.

If the patient is making slow progress, it is important to examine the impact of the environment on the patient. It might be that there are excessive unwritten demands on patients – a rehabilitation environment that stresses obedience to rules can make patients over-reliant on staff and does not foster independence. Patients who are independently minded might become frustrated and hold back in their efforts or they may react angrily against a system that encourages rules that they interpret as petty and/or confining. If the environment is not flexible enough then the only way that patients may impose their independence is not to do what is expected (Elliott et al 2002). Such situations may provoke an escalation of conflict and further non-concordance.

Developing appropriate relationships with staff

A stereotype of people with disabilities is that they are passive recipients of care (French 1996). Patients can become more involved in health care when staff behave appropriately towards them.

Semi-comatose patients in a critical care unit where nurses were trained in empowering behaviour – similar to psychotherapeutic behaviours of genuineness, empathy and positive regard (Ellis et al 1999) – improved more than a control group (Lauro de Los Rios Castillo and Jose Sanchez-Sosa 2002). However, for such enhanced care training to begin, staff should have good relationships with each other. Thus the quality of interaction with patients depends on the quality of interaction between staff members. Staff can be trained to be empathic, but maintaining such an approach depends on the support they receive in the post-training environment (Bloom 1994).

Training programmes for staff in rehabilitation are still in their infancy (Forster et al 1999, Salmon 2002). Kollias-Greber (1998) discusses a programme that includes guidance on interacting with different types of personalities, as well as culturally sensitive interactions, developing trust and communication and breaking bad news. Health professionals may initially feel awkward learning these skills (Stein-Parbury 1994), but good care should be of the same quality as that offered to a member of one’s family (Savage 1995).

**Encouraging patients to develop appropriate relationships with staff**

Health professionals can enhance the care they provide by developing a trusting relationship with patients and by taking time to get to know and understand them. They can actively listen to what patients say for content and feelings (Stein-Parbury 1994). By talking to patients, and finding out more about their individual personalities, staff can make the experience of rehabilitation more mutually rewarding (French 1996, Maclean et al 2002, Pound et al 1999).

Empathy can be used to demonstrate that patients have been accepted and understood, thus enabling the nurse-patient relationship to develop. These skills can be improved by reflection on past interactions between patients and health professionals. Disability may provoke powerful reactions in staff, such as pity, revulsion or inadequacy because they feel unable to help when they think they should (Laatsch et al 1993, Laposa and Alden 2003). In these circumstances discussion of individual cases with colleagues can defuse emotions (Conway 1996).

The desired outcome is to create an environment where patients and staff feel accepted, understood and valued, and where patients find the strength and support to make decisions about their care (Kagan and Evans 2001).

**Managing upsetting feelings while maintaining hope for the future**

The circumstances surrounding sudden disability may have been traumatic. Some patients may re-adjust with short-term counselling (Roberts et al 1995), while others might need further help, particularly if they experience post-traumatic stress disorder. This can be recognised when memories of a seemingly life-threatening situation are involuntarily re-experienced (Zayfert et al 2002).

Many patients find it difficult to adjust to the limitations imposed by chronic disease. Some react against the fatigue associated with chronic disease and regard the ensuing reduced activity level as a traumatic failure. However, those who are less pessimistic about the nature of fatigue at the onset of symptoms have a better outcome (Chalder et al 2003).

Depression associated with physical illness presents in two ways: either as a physical effect of the illness itself or as thoughts patients develop about the negative effect of the illness on their lives. This form of depression can often be treated using activity scheduling (Williams 1992) (Box 1). This therapy seeks to restore the range and quality of the patient’s activities by carefully selecting those of
demonstrated reinforcement value to the patient. **Helping patients to manage upsetting feelings** Through observation and interview health professionals can determine if patients are having difficulty adjusting to their new situation. Patients should be assessed for signs of anxiety and depression. Symptoms include sadness or aggression in conversation, a foreshortened view of the future, apathy and undue preoccupation with symptoms (Williams 1992).

Cognitive behaviour therapy may be used when depressive thoughts are more accessible and the patient feels able to talk about them (Laidlaw et al 2003). This encourages patients to consider their automatic thought patterns and to reflect on other ways of thinking that might be more appropriate. The desired outcome is that patients will avoid rehabilitation activities less and be able to discuss trauma without experiencing excess emotion.

**Preserving a competent self-image despite dependency**

People usually have assumptions of invulnerability, meaningfulness in life, personal control and positive self-regard. These assumptions are challenged by traumatic events such as being diagnosed with a serious illness or being the victim of crime. The person then initiates a search for meaning to restore these basic assumptions (Ellefsen 2002).

An individual’s behaviour is influenced by the judgement that he or she makes of his or her situation. During the adjustment phase at the beginning of rehabilitation, patients who have a physical body change often regard the disability as being worse than how others view it. For example, patients who have had a limb amputated can fear the disability more than needing to ‘master’ them, which is a more feasible proposition. Correspondingly, their view of themselves changes and they become more realistic, incorporating the disability into their lives in a more positive way. They accept that their body has undergone enforced changes and have a more neutral view of the vagaries of a changed body image (Norris 2000).

**Box 1. Activity scheduling**

This addresses the behaviour components of depression and is most useful for physically inactive people. Patients should record their mood and activities. Those activities associated with a higher mood should be repeated.

Examples of activities are:
- Being with someone I love
- Having a cup of tea with friends
- Listening to the radio
- Thinking about something good in the future
- Sitting in the sun
- Listening to music
- Attending a religious service
- Watching animals
- Reading
- Planning trips

(Maintaining relationships with family and friends to provide support)

The family can be an important resource for patients in helping them to adjust (Clark 1999). However, family members may require advice to help them cope with the patient. This advice may reduce stress and disturbance within the family if it is provided during the rehabilitation programme. Care can be focused on how a potential stressor interacts with family resources for dealing with crises and what meaning the family attaches to the event. For example, impulsive caregivers who over-react to challenges have a poorer outcome than those who adopt a calmer problem-solving approach (Elliott et al 1999).

**Helping patients to maintain relationships with family and friends** Health professionals can plan and co-ordinate support for patients following discharge by discussing with significant family members or carers the degree of practical and emotional support and frequency of contact they can provide. It is also important to establish whether relationships have changed since the disability. A separate conversation with significant others may be needed. Care should be taken to encourage

(Gallagher and Maclachlan 2001), perhaps projecting onto others their own revulsion about the affected limb.

An artificial limb may be used to conceal a disability and so restore body image. It might maintain self-image by being visible, for example, a soldier on active service for his country justifies the limb loss. To help adjust to the new image, patients may find peer support from others with similar conditions useful.

**Helping patients to preserve a competent self-image** Health professionals can discuss with patients aspects of their lives other than the disability. Patients may feel that their personalities have been developed in some way by their disability. For example, they may feel amazed that they have reacted so well in coping with a trauma. Reinforcing activities, such as leisure, recreational skills and simple tasks (Williams 1992), that are in line with the patient’s new body image, should be arranged. Patients with similar disabilities may wish to join discussion groups.

Encouraging patients to be as independent as possible increases their confidence in their ability. The desired outcome is that patients realise that they are able to ‘manage’ their symptoms rather than needing to ‘master’ them, which is a more feasible proposition. Correspondingly, their view of themselves changes and they become more realistic, incorporating the disability into their lives in a more positive way. They accept that their body has undergone enforced changes and have a more neutral view of the vagaries of a changed body image (Norris 2000).
patients to become actively involved in this process so that they can appreciate that carers have their own dimension in the rehabilitation process. Carers should be encouraged to recognise their behaviour as a part of the caring process. Advice on what to say to carers is outlined in Box 2. This could be made into a handout for carers to legitimise and reinforce the advice health professionals may wish to give. The desired outcome is that any deficiencies in coping requirements, for example, social, emotional, financial and practical, can be acknowledged and planned for in advance of patient discharge.

Box 2. Minimising carers’ distress

Normalise the emotion
Anger, frustration and sorrow are natural emotions for close relatives of patients with disabilities to experience.

Carer’s health first
Carers should take care of themselves first if they are going to be able to continue providing good patient care.

Maintain an even-tempered relationship
Try not to feel bitter and resentful towards the dependent person.

Own choice
Carers should rely on their conscience and judgement when in conflict with the patient or other family members.

Stay social
Carers should try not to let caring for the dependent person interfere too much with their social activities.

(Adapted from Cousins et al 2002)

Prefering for an uncertain future

People with disabilities experience exclusion and social stigma. This is reflected in physical restrictions like access to buildings and services, and in the reactions of other people (Heatherton et al 2000). However, the Disability Discrimination Act 1995 has helped to lessen these inequalities. Patients with a disability do not know how other people will behave towards them until they meet them. Strangers may reject people with a disability by staring at them, or they may be hostile or ignore them (Bradbury 1996). A single adverse experience can affect patients’ future social life. The anniversary of their first public appearance since the disability can be an occasion of great anxiety and distress. Some patients repeatedly experience unease each time they venture out.

REFERENCES


The patient's physical condition often fluctuates and so his or her abilities will vary from day to day, making every situation different and unpredictable. Thus, the psychological impact of the disability can only be managed, not mastered (Devins and Binik 1996). Patients need to accept their disability before they can cope with the reactions of others. It may be helpful to develop a script which patients can use to explain their disability to others when asked.

Helping patients to prepare for an uncertain future Health professionals can discuss with the patient how he or she feels when meeting people for the first time. They may need to work together on possible scripts encouraging the patient to think about what to say to strangers about his or her disability. The desired outcome is that patients will feel more confident in meeting people and will be realistically cautious, but optimistic, about the future.

Conclusion
This article has extended Moos and Schaefer's (1984) model by incorporating recent work on coping responses; the concepts of control, health value and self-efficacy; social skills; cognitive behaviourism; specific psychological survival skills for carers; and strategies to help patients deal with stigma. The seven psychological challenges are not a series of stages that all patients will experience. Not all of the challenges will be applicable to all patients in rehabilitation. Each of the challenges should be checked with the patient to highlight those that may explain difficulties in other areas. For example, anxiety might have repercussions for social functioning and rehabilitation potential. Moos and Schaefer's (1984) framework could be used to heighten awareness of some of the difficulties experienced by patients during rehabilitation rather than providing prescriptions for action at each stage of the model with all types of patients.

Psychological aspects of patient rehabilitation are often regarded as vague and difficult to negotiate. However, this article has provided some information on how these can be addressed. Identifying crisis stages allows definite courses of action for health professionals to follow. Such action aims to liberate patients from much of the mental difficulty in which many find themselves, allowing them to fulfill their potential through the rehabilitation process.