COPING WITH DISFIGUREMENT 2: STRATEGIES FOR PATIENTS

AUTHOR Suzanne Millstone, MA, BA, AdvDip Couns, Dip Supervision, MBACP, is health professional adviser and clinical supervisor, Changing Faces.


Part 1 of this two-part unit identified the various causes of disfigurement, examined some of the myths associated with it, and explored the feelings and behaviours of those affected and their families. This second part examines ways in which nurses can help patients to deal with anxiety and challenges.

GOOD OUTCOMES
The four factors influencing outcome are:
● Social support;
● Information and involvement;
● Perception of the disfigurement’s severity;
● Social interaction skills.

Social support
Social support has been defined as the information that leads people to believe they are cared for and loved, esteemed and a member of a network (Cobb, 1976). In the early days after discharge from hospital, people with disfigurement will value spending time with an individual or a small group of people. This will help them to feel shielded from the social intrusion characteristic of many first encounters (Partridge, 1990).

However, not every patient will have a supportive family network or group of friends. Some will rely solely on support from social services or a local support group. It is therefore necessary to identify:
● The patient’s needs;
● How their social network responds to the changing needs;
● The family’s needs.

Information and involvement
Patients and relatives alike will need access to explanations and information, which will help to make their fears manageable.

LEARNING OBJECTIVES
1. Understand the importance of social skills training
2. Know how you can help patients to think about how they will manage awkward social situations

Perceptions of severity
Kleve and Robinson (1999) highlighted the importance of ‘perceived severity’ or how noticeable a disfigurement is – rather than objective severity – as the critical indicator of good or poor outcome. In other words, it is how individuals interpret their injury that is critical to long-term recovery. Self-appraisal, personality and coping style are more important in how a person copes than the objective view of severity. Perceived severity is also likely to have an impact on individuals’ behaviour in terms of developing good social skills (Kleve et al, 2002; Kleve and Robinson, 1999). Perceiving appearance problems to be severe is more strongly related to poor adjustment than objective severity (Moss, 2005).

Social interaction skills
The final factor identified as predictive of good outcome is the number and variety of positive, non-avoidant coping strategies used by the individual (Kleve et al, 2002; Clarke, 1999). Social competence has been found to be one of the better predictors of adjustment (Kapp-Simon, 1992). Rumsey et al (1986) said that high levels of social skills can help overcome any potential negative effects of disfigurement on social interactions.

Social skills are central to managing the impact of disfiguring injury or disease and, most importantly, these skills can be learnt (Robinson et al, 1996). Indeed, Clarke (1999) pointed out that it is behaviour rather than disfigurement that predicts successful outcome in social situations. Thompson and Kent (2001) argued that providing people with the skills to deal with difficult social interactions is likely to be empowering.

Many people with ‘difference’ experience psychosocial disturbances, and need interventions to help them cope (Bessell and Moss, 2007). There is an unmet demand for information to support psychosocial adjustment (Picker Institute, 2007).

UK charity Changing Faces suggests that all patients with disfigurement should be introduced to the idea of how to answer
questions about their appearance before discharge and for at least two years after in outpatient appointments. The aim is to avoid a pattern of social avoidance due to fear of intrusive questions, comments and staring.

Teaching patients how to assist with dressings introduces the idea of self-management in the immediate post-operative period. This one-to-one activity in hospital can also be used to discuss the importance of developing basic strategies, for example, answering questions about appearance (Clarke and Cooper, 2001). Nurses in community settings and those carrying out routine health monitoring are in an ideal position to explore and identify patients’ social difficulties and concerns following discharge (Rumsey et al, 2002).

Here are examples of key questions to ask:
- ‘Do you feel that your medical condition affects your appearance?’
- ‘How noticeable do you feel it is to other people?’
- ‘How much does this worry you?’
- ‘Is there anything that you don’t do as a result of your concerns about your appearance?’
- ‘Are there any particular strategies that you find helpful in coping with your concerns?’
- ‘What do you say if someone asks you about your appearance?’

**GRADED APPROACH**

Changing Faces uses a graded approach to help people increase the number and variety of coping strategies with which they feel comfortable. This enables patients to feel prepared and to develop strategies during controlled exposure, for example, on visits to the patient common room, taking meals with other patients or on accompanied trips around the hospital.

At the very beginning of this process, patients may only feel comfortable nodding to another person before they can perhaps smile or say ‘Hello’. Practising these strategies in the safe environment of a hospital will help them to build confidence for when they encounter people outside.

Another example of the graded approach concerns helping patients to think about what they will say in response to questions about their appearance – beginning in the hospital setting, then after discharge. Here are four graded ways of answering: ‘What happened to your face?’, beginning with minimum information, and graduating to a more interactive conversation:
- Minimum information and close the subject: ‘I had surgery but I’d rather not talk about it at the moment.’
- Answer and change the subject: ‘I have a condition…. Are you new to this area?’
- Potentially open up the topic: ‘I have burns and I have to be careful in the sun…’
- Use humour to break the ice: ‘At least people don’t forget me!'

Helping patients to experiment with and experience these graded strategies and responses in a ‘safe’ one-to-one setting will encourage them to decide which type of response they feel comfortable with, and will gradually build up their self-confidence to expand their repertoire.

Patients may not always wish to respond in the same way, nor should they feel obliged to do so. They can respond in a firm and assertive manner in these situations without appearing rude.

**SIGNPOSTING**

Sometimes patients may be reluctant or feel they are not ready to think about how they might respond in social situations, possibly due to factors such as age or gender. Or they may prefer to access information about their condition at a later time. In these instances, it is helpful to provide them with resources (see box, right).