Providing effective support for patients facing disfiguring surgery

Ben Bowers

Abstract

Surgery for head and neck cancer can leave patients with obvious facial disfigurements. Some individuals adjust remarkably well to their altered appearance and require very little emotional support. Conversely, individuals with poor coping skills or limited support from those close to them can become socially isolated and depressed. Nurses, caring for patients during their hospital stay, are in the ideal position to assess how they are emotionally adapting to having a disfigurement. By listening to the patient, and their family's concerns, nurses can make a real difference to their recovery and quality of life. Through facilitating the development of the individual's practical coping skills and confidence in social situations, nurses can help patients to start to constructively adjust to their new appearance. It is crucial to put patients and their families in touch with ongoing support before they go home.

Key words: Altered body image ■ Disfigurement ■ Head and neck cancer ■ Ongoing support ■ Postoperative care ■ Stigma

Having surgery for head and neck cancer is an emotional and traumatic experience. Patients undergo radical surgery after experiencing a host of diagnostic investigations in rapid succession. They then face the likelihood of needing debilitating radiotherapy or chemoradiation (National Institute for Health and Clinical Excellence [NICE], 2004). Simultaneously, the patient must come to terms with the physical and emotional consequences of having disfiguring surgery.

The face is one of the most valuable and visible parts of the body. It serves as the primary medium for communication, emotional self-expression and identification (Dropkin, 1997; Katz et al, 2003). Consequently, surgical changes to the face and neck are apparent to even the casual observer and can deeply impact on their social interactions and emotional wellbeing.

Nurses are in a unique position of being able to support individuals in coming to terms with their altered appearance during their hospital stay. As the professional group with the closest continuous contact with patients, nurses are ideally placed to listen to their concerns and provide appropriate support (Price, 1990; Edwards, 1998; Feber, 2000). Furness (2005) interviewed facial surgery patients treated in a variety of hospitals throughout the United Kingdom, and their families, and found they felt that healthcare professionals underestimated or neglected their psychological and social rehabilitation needs. Even nurses working frequently with patients who are adjusting to disfiguring head and neck surgery rate their skills in dealing with the social aspects of rehabilitation as significantly weaker compared with their skills in physical aspects of rehabilitation (Clarke and Cooper, 2001).

Supporting the patient's adjustment to their altered appearance following head and neck surgery can be challenging. Nurses sometimes fear that discussing how someone feels about their new appearance can stimulate the patient to unleash strong emotions such as anger and despair (Wilkinson, 1991). Practitioners may feel they lack the communication skills to address the patients concerns constructively (Wood and Bisson, 2004). Dealing with negative feelings can prove emotionally draining and time consuming for the nurse. Nevertheless, adequately addressing each individual's emotional needs is a crucial part of their rehabilitation process (Edwards, 1998; Price, 1999; Furness, 2005). To enable practitioners to provide more effective support, this article explores the impact of having disfiguring surgery and how nurses can use practical interventions and teaching strategies to facilitate the patient's social and psychological rehabilitation during their acute hospital stay.

Surgery

Every individual adjusts in a different way to disfiguring head and neck surgery (*Table 1*). Evidence demonstrates that how distressing the individual finds their situation is not dependent on the physical severity of their disfigurement (Newell, 2000; Katz et al, 2003). A patient may not have any lasting functional disfigurement following a neck dissection, yet they may feel self-conscious in public because they are aware that one side of their neck is thinner than the other. Extensive oral surgery can leave an individual with involuntary drooling and only able to eat a puréed diet. These problems may limit where and with whom the individual feels comfortable socializing. Conversely, someone else who has had physically extensive surgery may adapt exceptionally well; for example, an individual who has had their larynx removed and is left with an obvious stoma in their neck may quickly adjust to communicating in a different way and feel comfortable interacting with strangers.

How someone adjusts relies on the degree of their disfigurement, the emotional value they place on their altered

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appearance, how comfortable they now feel in managing interactions with others and the quality of the support they receive from those close to them (Dropkin, 1997; Price, 1999; Newell, 2000; Relic et al, 2001).

Stigma

Patients who have undergone any disfiguring head and neck surgery are more likely to feel they are stigmatized by wider society (Goffman, 1963; Clarke, 1999). People tend to attribute a wide range of negative traits to an obvious disfigurement; for example, individuals can assume that someone who has a disfigurement is also intellectually impaired or has some form of undesirable personal traits (Morris, 1991; Feber, 2000). This is often experienced by patients with facial disfigurements when they come in contact with strangers and acquaintances after their surgery. In their company, other people may feel awkward, embarrassed, stare or simply opt to avoid any interactions (Clarke and Cooper, 2001). Strangers may ask personal questions or make comments that they would not normally consider socially acceptable to do in other situations.

Challenging and unpleasant social situations can cause a great deal of distress for the person trying to come to terms with their disfigurement. Uncertain of how to behave, fearing causing offence and wanting to avoid unpleasant situations, the individual may chose to limit their social interactions. By avoiding new situations, individuals adjusting to their new appearance are unable to build up the everyday social skills necessary for developing their confidence in the long-term (Clarke and Copper, 2001; Furness, 2005).

Head and neck cancer can be associated with maladaptive coping skills such as heavy drinking and smoking (Dropkin, 1997). These traits can limit the social support and types of friendships the individual has and can make adaptation to their altered appearance more difficult (NICE, 2004). Individuals who do not have the coping skills and ability to constructively explore new social situations are more likely to become anxious and depressed (Devins et al, 1994; Watt-Wilson and Graydon, 1995; Wood and Bisson, 2004). To support patients in constructively adjusting to their disfigurement, it is crucial to assess what type of support and coping skills they possess and how they use them throughout their hospital stay.

Preoperative preparation

Many patients will have major fears about what their surgery will entail and the extent of their postoperative deficits. Providing good preoperative information enhances a sense of control, reducing anxiety by explaining what the upcoming procedure will involve, and how it will affect the patient and their family (Feber, 2000). Newell et al (2004) and Furness (2005) found that head and neck patients were more satisfied with their treatment if they were given the opportunity to ask questions, adequate time to discuss issues and received information that was tailored to their needs. Patients are more likely to make a better recovery if they have had a chance to discuss their concerns (Lister, 2001; Furness, 2005).

The hospital's head and neck clinical specialist nurse (CNS) will identify patients undergoing disfiguring surgery and offer additional preoperative information to help them and their families prepare for the potential effects of the surgery. Individuals who are undergoing extensive surgery benefit from meeting someone who has been through a similar operation and discussing their experiences; for example, meeting a successfully rehabilitated peer before undergoing a laryngectomy can demonstrate to the patient and their family that they can lead an independent life after treatment (Feber, 1998; Cady, 2002).

Information giving should be tailored to each individual's unique needs. Some patients are not ready or do not want to discuss the psychosocial implications of having their surgery in great depth (Cady, 2002; Furness, 2005). Occasionally, head and neck cancer patients need to undergo surgery a few days after their diagnosis. Although they will have discussed their treatment, they have not had the time to properly digest information or be psychologically ready to take on board the extent to which surgery will impact on their appearance.

The nurses looking after the patients when they come in to have their surgery are in the best position to assess what they understand at this time and be there to take note of their concerns. Patients often want professionals to truly listen

Figure 1. There is a need to look beyond just physical rehabilitation.

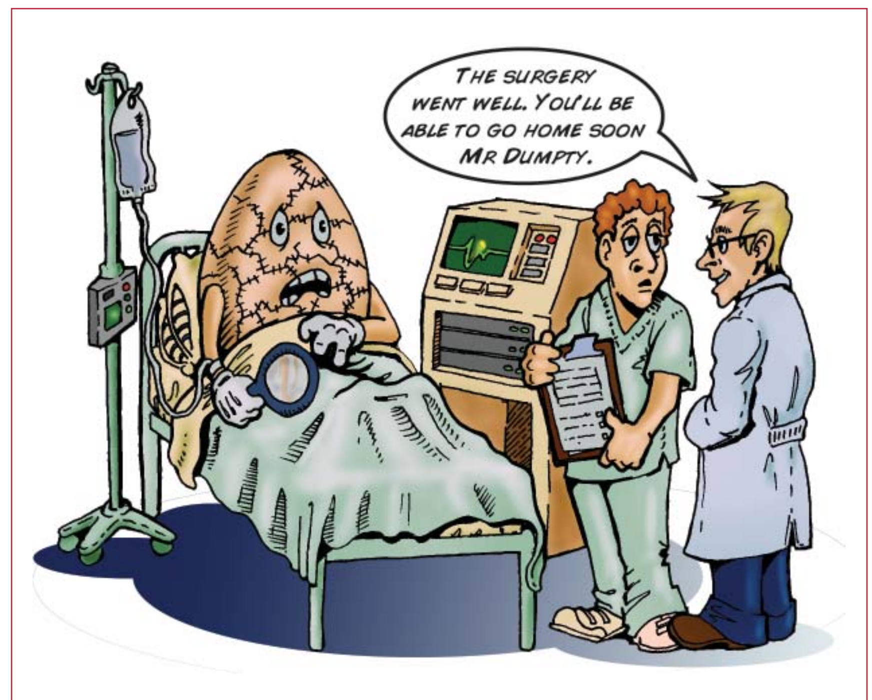

Table 1. Examples of disfiguring head and neck surgery

Surgery	Potential physical deficits
Radical neck dissection	Altered neck contour
Parotidectomy	Facial droop
Total maxillectomy with orbital exenteration	Facial defect, unilateral vision, loss of smell, difficulty with swallowing and speech
Total laryngectomy	Altered speech, neck stoma, decreased smell
Supraglottic laryngectomy	Difficulty with swallowing
Partial glossectomy	Difficulty with swallowing and speech

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to their worries, offer sincere support and provide palatable amounts of information at this particularly anxiety provoking point in their care pathway (Newell et al, 2004; Furness, 2005). Conversations may wonder far and wide as the patient rationalizes what lies ahead, e.g. pain, overcoming practical difficulties, such as eating or speaking, or deciding how best to 'account' for changes to family and friends. In turn, the nurse is then well placed to access further specialized support from other members of the multidisciplinary team, such as the speech and language therapists or the CNS, to best support the ongoing needs of the patient and their family.

Supporting family and friends

If someone is going to constructively adjust to their altered appearance they need reliable support from those close to them. The individual, who knows their relatives and friends still treat and consider them as the same person after their surgery, has a safe and supportive environment from which they can explore new and more threatening social situations (Price, 1999; Relic et al, 2001). The initial response of their relatives on seeing them after surgery means a lot to the patient. As Feber (2000) points out, relatives are often the first 'mirror' the patient uses to gauge the extent of their disfigurement. If family and close friends react unfavourably to their disfigurement, it will have a lasting impression on the patient and can impede their ability to emotionally adjust to their new situation (McCormick, 1995).

Just as the patient must adjust to their appearance after surgery, those closest to them need support in coming to terms with the disfigurement. It can be shocking and upsetting for the family to see the patient for the first time after their surgery. Close relatives and friends may become distressed with themselves for feeling embarrassed, not knowing what to say or feeling initially repulsed by their love ones new appearance (Price, 2000).

Relatives and close friends who will see the patient immediately after their operation need to be coached and supported carefully (Feber, 2000). They should be made aware that any changes in appearance will be exacerbated by postoperative bruising and swelling. By being talked through what to expect when they first see the patient they will be better prepared on seeing their relative after extensive surgery. The patient's family should also be coached on how to give positive and realistic reinforcement to encourage the patient's rehabilitation. Conversely, relatives can offer excessive emotional support and the patient may become overpowered or come to begrudge well-meant attempts to help them. It is at this juncture that the nurse needs to tactfully suggest that the patient is given some time and space to adjust to their situation (Feber, 2000; Price, 2000).

As those closest to the patient, spouses often feel that they must be emotionally strong for their partner. However, even the relative who appears to be coping exceptionally well may be hiding a great deal of distress. In the postoperative period, families value talking frankly with the nurses about their own concerns and the long-term implications of their relative's disfigurement (Edwards, 1998). Through offering time and attention to their needs, the nurse is able to assess how well relative's are truly coping, and if appropriate, direct them to sources of further emotional support through their GP, the CNS or local support groups.

Initiating self-care

A key role of the nurse in the postoperative recovery period is to support and educate patients to take on self-care. The contours of face or neck will have altered after surgery, making tasks like applying make-up or shaving more problematic, and anyone who has had extensive surgery will need to learn new functional skills such as undertaking their own stoma care or caring for their prosthesis. Taking on these new skills can cause patients a great deal of anxiety at first (Feber, 2000; Dropkin, 2001). However, engaging and involving the patient in their own care early on in the postoperative period reintroduces the idea of control, self-management and independence.

Through engaging patients in their own self-care the nurse can constructively support them as they come to terms with the severity and extent of their disfigurement. As patients take on self-care tasks they learn strategies to confront, adapt to and start to accept their disfigurement. Certainly, performing increasingly familiar self-care activities has been shown to reduce anxiety and improve coping skills in the first 5 days after head and neck surgery (Dropkin, 1989; 2001). Conversely, the pace of rehabilitation and throughput of patients can mean the pressure on developing self-care is great, precisely when patients are struggling to believe that they can influence their difficult situation (Cady, 2002; Furness, 2005). When the individual takes an interest in their grooming after surgery they are preparing themselves for seeing other people and are seeking social acceptance.

A crucial part of supporting self-care skills is being there when the patient first looks in the mirror. Many patients vocalize how alarmed they are to see their appearance for the first time (Wood and Bisson, 2004; Furness, 2005). This can be an even more traumatic experience if there is no one there that the individual trusts to listen to and discuss their concerns. Patients who continually avoid looking at their face are often less able to adjust constructively to their new situation (Feber, 2000). It is important to encourage the patient to see their appearance and be with them when they first look in the mirror. Remind them that postoperative swelling and bruising will temporarily distort and intensify the changes in their appearance. Support the patient in expressing their feelings and answer their questions truthfully and tactfully (McCormick, 1995).

The patient will read a lot into how the nurses treat and react to their new appearance. Patients often view nurses as knowledgeable and honest advisers because they are not as emotionally involved as their relatives or friends (McCormick, 1995; Price, 2000). Therefore, if the nurse reacts unfavourably to their disfigurement this can have a lasting impression on the individual and distort their perception of their situation. It is important to continually give positive but honest feedback to patients as they take on their self-care skills. Using good eye contact and unhurried conversation demonstrates to the patient that their appearance is socially acceptable.

Resocialization

It is important for the patient to venture out of their room and start socializing with others during their postoperative

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hospital stay. By interacting with staff, family and other patients, individuals can see how others react to their disfigurement. This will allow the individual to adjust how they present themselves and develop confidence in managing new encounters (Dropkin, 1989). If the patient gets positive feedback from those they meet, they will build up their confidence and this should replace the vicious circle of expecting negative reactions and behaving shyly or avoiding interactions (Clarke, 2007).

The ward is a relatively safe environment where staff and other patients expect to see people who are recovering from surgery. This does not mean that the individual will not experience negative remarks or staring from other patients and visitors. Indeed, the patient needs to learn how to deal with other people's reactions, embarrassment, staring and discomfort as early as possible so that they can develop constructive coping techniques (Hagedoorn and Molleman, 2006; Clarke, 2007).

Crucially, during their hospital stay, the individual has some control on where they go and can rely on having the support and understanding of the professionals around them. The nurse is in the ideal position to observe the patient's postoperative progress in socializing with others and stimulate them to explore new situations (*Figure 2*); for example, if the individual is anxious about walking down the ward for the first time the nurse could offer to go with them. Once the patient is comfortable doing this on their own, the next step could be to suggest they spend some time in the day room. The process involves graded exposure to new encounters, with the nursing staff providing support and debriefing to help the individual decide how they faired and how they could cope in the future (Dropkin, 2001; Clarke, 2007).

If a social situation does not go as well as the patient expected or wanted the nurse should listen to their concerns. There is unlikely to be an easy answer to the patient's apprehension and everyone needs time to adjust to their postoperative appearance. Often, just having someone there that they can trust who will listen to their concerns will bring the individual relief (Wood and Bisson, 2004). Through discussing how a situation could have been handled differently with the nurse, the patient may find another approach they would like to try out in the future (McCormick, 1995; Furness, 2005). For instance, instead of putting their head down when a visitor stares at their facial disfigurement, the patient may find that if they nod or smile at the other person they will get a similar greeting back. There are a number of useful booklets available through the charity 'Changing Faces', which nurses can use with patients to support them in adjusting to their disfigurement (*Table 2*). The charity also runs regular courses which have been shown to help professionals develop their skills and knowledge to effectively support patients in dealing with social situations (Clarke and Cooper, 2001).

Nurses need to feel able and comfortable to discuss patients' concerns (Wood and Bisson, 2004; Furness, 2005). It can be daunting to enter such conversations when patients can unleash a multitude of emotions and concerns which the practitioner feels unable to address. It can help the patient to rationalize their situation by reminding them that, despite having the surgery, they are still the same person they always have been and highlight their successes (Feber, 2000). The individual may benefit from extra input from the CNS or a referral to a counsellor if they are having complex problems in adjusting to their disfigurement (Woods and Bisson, 2004; NICE, 2004).

Figure 2. Documentation of postoperative resocialization activities.

Activity observed by nursing staff	Postoperative day
Interaction with family (listening/gesturing/talking)	
Interaction with staff (listening/gesturing/talking)	
Interaction with other patients (listening/gesturing/talking)	
Up and around room	
Up and around the ward (corridors/communal areas)	
Up and outside the ward (trips out/walks outside)	

Signed........................

Note: If activities are unlikely to be performed by day 7, reevaluate the need for more intensive psychological and emotional support

From: Feber (2000); Dropkin (2001)

Table 2. Sources of ongoing support for head and neck cancer

Source	Address	Website
Macmillan Cancer Relief	Macmillan Cancer Support 89 Albert Embankment London SE1 7UQ Telephone: 0808 808 2020	www.macmillan.org.uk
Cancerbackup	Bath Place Rivington Street London EC2A 3JR Telephone: 0808 800 1234	www.cancerbackup.org.uk
Changing Faces	Changing Faces The Squire Centre 33-37 University Street London WC1E 6JN Telephone: 0845 450 0275	www.changingfaces.org.uk
National Association of Laryngectomee Clubs	Lower Ground Floor 152 Buckingham Palace Rd London SW1W 9TR Telephone: 020 7730 8585	www.nalc.ik.com
Head and Neck Support group	See members of the local head and neck team for details	
Tracheostomy UK	Website access only	www.tracheostomy-uk.com
British Red Cross Skin Camouflage Service	9 Grosvenor Crescent London SW1X 7EJ Telephone: 020 7235 5454	www.redcross.org.uk

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Continuing support

The most emotionally difficult time for patients and their families can be when they get home. Individuals often report that the initial relief of surviving the illness is overshadowed by the reality of the impact disfiguring surgery has on their lifestyle (Clarke, 1998; Newell et al, 2004). They must find a way to cope and present themselves to others in every public interaction. Moreover, patients may need to have debilitating oncology treatments. This will further drain the individual's physical and emotional strength and there is no guarantee that their cancer will not return (NICE, 2004). Individuals can quickly feel isolated, restricted in their social activities and unsure of where to turn for help (Watt-Wilson and Graydon, 1995; Newell et al, 2004).

It is crucial to ensure that patients and their families have access to ongoing community support once they are discharged (*Table 2*). They should be given the contact details of the CNS and know they can access their advice (Edwards, 1998; NICE, 2004). Patients should also be referred to the community nursing team before they are discharged home. The team, along with the GP, is best placed to provide ongoing support for the patient and their family (Feber, 2000; Relic et al, 2001).

Some patients benefit from learning how to apply specialist camouflage make up to play down their facial disfigurement. However, depending on the individual's disfigurement and skill in applying make up, the creams can draw attention to the feature rather than disguise it (Clarke, 1998).

When the patient is at the stage where they want to constructively build their confidence in social situations, they can benefit greatly from undertaking social skills training (Partridge, 1998; Clarke, 1999). The charity 'Changing Faces' offers easily accessible social skills training courses, telephone support and face-to-face support groups for patients who have a disfigurement. Individuals and their families can also gain a lot of support and relief from knowing they are not alone by meeting with peers through local head and neck cancer support groups (Edwards, 1998; Relic et al, 2001). Supply patients and their families with the contact details of support and charity organizations available before they are discharged home (*Table 2*). This will enable them to access further support when they are ready.

KEY POINTS

- Surgical changes to an individual's face and neck can deeply impact on their social interactions and emotional wellbeing.
- Nurses are ideally placed to support their patients, and their families, in coming to terms with their disfigurement.
- Through listening to and acknowledging the patient's and their relatives' feelings, the nurse can help them access appropriate support.
- Patients may benefit from extra input from the clinical nurse specialist or a referral to a counsellor.

Conclusion

It is natural for individuals to have a wide range of emotional reactions as they come to terms with having disfiguring head and neck surgery (Wood and Bisson, 2004). Regardless of the severity of the surgery, some patients will be realistically optimistic about their situation, while others risk becoming isolated and depressed. By listening to the patient and their family's concerns, nurses can make a real difference to their recovery and quality of life. Effective nursing support involves facilitating the development of the patient's practical coping skills and confidence. The individual and their family are less likely to be restricted by their new situation and feel neglected if they are put in contact with appropriate ongoing support before they are discharged home. BJN

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