Rehabilitation and stoma care: addressing the psychological needs
Barbara Borwell

Abstract
Stoma surgery may be required for many reasons. The circumstances in which intervention is required, with possible permanent changes to the patient’s conventional body image and lifestyle, will influence psychological recovery (Borwell, 1997; Black, 2000). Within a diverse multicultural society, addressing the individual psychological problems of the effects of mutilating surgery due to acute/chronic illness can be particularly challenging for health professionals. This can be further compounded if the patient has a physical or mental disability. Stoma care nurses play a vital role in supporting the family of the patient as a whole. Communication is key, encouraging open and genuine dialogue. Listening to patient and family anxieties will facilitate family cohesion and support. Families and/or the significant other of the patient face levels of distress equal to that of the patient, and need to be included in our care package. Psychological adaptation and successful rehabilitation of the patient are potentially achievable by a structured and complete assessment, assisting further understanding of patient, family and social needs. However, existing or additional anxieties will only be revealed if nurses can overcome personal communication difficulties (Borwell, 1997; Black, 2000).

Key words: Psychosexual awareness ■ Rehabilitation ■ Stoma care ■ Wellbeing

The focus of rehabilitative care should be on health and quality of life (QOL). In terms of QOL, rehabilitation needs to centre on parity of care, therefore minimising impairment and disability, and maximising recovery and social participation.

The notion of ‘wellbeing’ is conducive to the concept of rehabilitation. ‘Wellbeing’ can be about how one is feeling and likened to a high level of self-esteem, incorporating all those domains which make up for a ‘good life’. This includes social, mental and physical features (World Health Organisation, 2001). Placed within this context the term ‘psychosexual wellbeing’ for each individual may allow sexuality and sexual health to be addressed openly and integrated within nursing practice (Davis and Taylor, 2006).

Equality of care through the full, free and sensitive flow of information throughout the patient journey is essential and is recognised in National Health Service policy (NHS).

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(Deartment of Health (DH), 2000; DH, 2001). It is also acknowledged that all patients have health needs which include psychosocial as well as disease and treatment. The necessity of education and the imparting of timely information, whether good or bad, is now acknowledged by health-care professionals.

The information process should include recognition of a patient’s right to know their diagnosis, treatment options and outcomes, and how their condition after treatment/surgery might affect other aspects of their life. Assessment of patient understanding at the point of diagnosis suggests that the establishment of the required level of information about his/her condition can enhance recovery and their ability to cope. Establishing and facilitating relationships with patients can determine the level of involvement pertinent to decision-making and care. This is a challenging aspect within the debate on issues surrounding informed consent and the quality and consistency of communication between health-care professionals and their patients (White, 2001). Rehabilitative stoma care aims to provide quality of care based on the biographical and general health information acquired at the initial interview, through a comprehensive assessment.

Communication and information
Nurse involvement in providing and coordinating multidisciplinary communication and contribution to the ‘care package’ is essential to patient well being. Surgery requiring stoma often affects those patients with special needs and yet these needs are often inadequately met, both in hospital and in primary care (Borwell, 2005). Cooper and Guillelbo (1999) explored the personal experiences of people with a learning disability and indicated a number of concerns, including hospital phobia, communication difficulties and unsatisfactory care.

Nursing assessment should not distinguish between the fundamental needs of a multicultural, often older, patient group. Planning care should include enquiry into the patient’s spiritual and religious beliefs and practices, or lack of, and what influence this could have on future care. This would enable patients to follow care compatible to their religious beliefs and practice (Neuberger, 1998).

Preoperative
Successful rehabilitation starts in the preoperative phase, where supportive counselling and psychological preparation of patients and their significant other/close family is essential. It aims to restore them to the lifestyle enjoyed preceding diagnosis surgery/treatment. The stoma care nurse is ideally placed to coordinate the elements of rehabilitation, with communication
and support from the multi-disciplinary team. Sound preoperative information enhances patient empowerment. Explanation on why stoma surgery is necessary and what this involves is important. Information such as the type of stoma raised, whether it would be temporary or permanent, whether this is curable or palliative and how it might impact on patient and family, can all influence the long-term psychological conclusion for the patient (White, 1998; Feber, 2000).

Someone who has endured a chronic debilitating condition that has imposed many lifestyle restrictions, like ulcerative colitis, will possibly view surgery with formation of stoma more positively than a cancer diagnosis. The latter produces anxiety, which can impair the absorption and retention of information about the consequence of treatment. A stoma, in this instance, would be a constant reminder of the patient's circumstance. Other considerations should include the current social, biological and psychological health status of the patient. Any previous history of psychological illness should be noted, and the patient referred for a detailed psychiatric assessment (White, 1998).

Preparation for living with the implications of body image changes include a consideration of the patient's perception of how they feel their condition has already affected their useful functional abilities, and sexual and lifestyle status. Anticipation of the loss of bodily composition and function through forward planning allows the person to predict the loss and reassess a more positive approach. The individual undergoing an emergency procedure, who is unable to anticipate this loss and grief process, will most likely experience difficulties in adapting to bodily image changes and function.

Carers, whether professional or family, may wish to be involved in the discussion, as they are likely to have anxieties. It is important to determine that the patient is in agreement with their involvement. Sometimes the presence of a carer will increase patient confidence, especially when important information has to be conveyed.

Evidence supports the need for pertinent information. However, difficulties have been noted when the provision of information has been wholly reliant on verbal discussion or where language difficulties pose a problem. An informal interpreter can generate problems, partly due to their lack of clinical knowledge (Arif, 2003). Family members should not be asked to act as interpreters, it is bad practice and they are unlikely to be able to be wholly objective listeners.

Most recognized organizations will ensure that suitably skilled interpreters are accessible for those patients who cannot speak or understand English (DH, 2000; DH, 2004). Resources linked to specific aspects of patient care to assist minority groups, and appropriately prepared literature, are available from many NHS hospital departments and welfare organizations (Henley and Scott, 1999). Therefore, a nurse has several considerations when the patient is at the preoperative stage: These are:

- the diagnosis and prognosis
- the relationship with the patient
- the culture and ethnic origin of the patient
- the physical and mental abilities of the patient
- the current lifestyle of the patient, and how it may be affected by the operation
- the patient's psychosexual 'wellbeing'.

Postoperative

Postoperative counselling, even if short term, can have a positive effect on the patient's conception of self, and their self-esteem (Watson, 1983). Patients should be encouraged to view themselves as 'normal' after surgery, the stoma being an inconvenience as opposed to a barrier or disability. Education about, and encouragement towards, self-care of personal health and welfare is paramount. Psychological recovery milestones are given by Borwell (2005). Patient:

- Begins to look at and touch stoma
- Allows others to look at stoma
- Expresses interest, asking questions about self-care
- Begins to take over responsibility for stoma care
- Socialises with patients and visitors.

The effects of stoma surgery/chronic illness on 'wellbeing'

Psychological

Body image and self-esteem are important to us all. Body image, the mental picture each individual has of their body, is developed from birth and formed through an evolving process. Learning about the body parts, here and in some instances, when and where they should function, is influenced by family, friends, community and cultural environment. Significance placed on physical appearance will affect values and attitudes about self-perception of body image changes. An individual's perception of body image can be affected in many ways, for example, by the effects of the natural ageing process or disease.

Anxiety, loss of self-esteem, grief and depression associated with chronic illness can all impair sexual function. Some couples may easily accept sexual cessation or limitations of sexual activity, for others, change of sexual function can lead to significant emotional crisis. Chronic illness can alter relationship dynamics. Fears and concerns about health, disease or medication can have emotional consequences affecting the significant other as well as the individual, resulting in relationship changes. An example of where this can occur can be seen in the patient with a stoma, and their family. Such a patient will have endured the misery of physical and psychological trauma due to mutilating surgery, skin problems and odour from pouch leakage. A specialist stoma care nurse utilising expert knowledge and skills can enable living with a stoma to become more acceptable (Wade, 1990). In contrast, some couples faced with a life threatening condition experience a positive change in relationships and intimacy.

Body image and sexuality are intertwined. The psychological suffering that often accompanies emotional and altered bodily changes, associated with gastrointestinal or urological disease, is part of a group of concerns which may affect the patients adaptation to a condition, including a reduction in sexual satisfaction (Borwell, 1997; Walsh et al, 1995). Diseases such as cancer are often viewed as more important than the loss of body part or bodily function. This loss of body part or function is a personal experience which represents a major transition in the patient's life and could potentially cause psychological problems (Hopson, 1981). Several studies indicate that an element fundamental to the rehabilitative process of adjustment and acceptance of bodily changes, is support from extended family, the community, employment and spiritual associates and local agencies (McGreedy, 2001; Krishnasamy, 1996).
Biological
Sexuality
An individual's self-concept is shaped by their personality, and expressed as sexual feelings, attitudes, beliefs and behaviour, with a heterosexual, homosexual, bisexual or transsexual orientation (Royal College of Nursing, 2000). Within this definition is the realisation that there is a need to recognise and support different sexual orientations, a need caused by the heterosexism that permeates our society.

The individual uniqueness of sexuality responds to maturational, physiological, social and psychological events. Consequently, illness, chronic debility and hospital admission will impinge an individual's self-concept, self-esteem and social relationships, thus affecting sexuality. Recognition of and the facilitation of the free expression of an individual's sexuality, without fear of exploitation, oppression, physical and emotional harm, is an essential part of sexual wellbeing (RCN, 2000).

Social
Sexual activity might be capable of being placed on hold, but sexual wellbeing remains a vital part of day-to-day living. In a multicultural society attitudes, practices and customs on what may be acceptable varies, vary enormously. Chronic illness becomes more common in the older person, but sexual dysfunction can be related more to the condition or its treatment, than ageing alone. Some patients are socially stigmatised due to a combination of physical, emotional and sexual factors (Grigg, 1997). The concerns of single, divorced or separated persons are often overlooked. Assumptions are made by health-care professionals that due to chronic illness, other disabling conditions or mental disability, a discussion about sexual wellbeing is irrelevant. There is little consideration of the fact that sexual activity does not necessarily require a partner. Often, assumptions are made that all couples are heterosexual, or, where there is no apparent partner, that the patient is homosexual. Homosexual, bisexual and transgendered patients, in or out of a relationship, will experience similar concerns, about sexual function as a heterosexual patient, in requiring equal support and counselling. Disclosure of sexual orientation and other sensitive concerns can be problematic for some patients and health professionals. Overcoming sexual stereotyping and discrimination is critical when discussing issues relating to sexual wellbeing, the patient's condition and its treatment.

Treatment effects on male sexual function
Sexual function can be impaired following any major stress; in time this should improve. The surgeon, or appropriate multi-professional team member, should communicate any potential risk of sexual dysfunction resulting from surgery or treatment, to the patient and partner in the pre-treatment phase. Bowel and urological cancer are usually associated with the older person, but can occasionally affect younger males. High dose radiotherapy may affect spermatogenesis with random recovery; ideally specialist counselling should be available and the option of sperm banking available.

Erectile dysfunction (the inability to have or sustain erection) may occur in men undergoing radical bladder or pelvic surgery, and can be transient or permanent, depending on the type of surgery performed. For example, the prostatic nerve plexus, critical for penile erection, can be damaged in such surgery. In addition, damage to the autonomic nerves, which control the vascular supply to the penis, resulting in sensory loss and erectile failure, can follow abdominal perineal excision of rectum, pelvic exenteration or radical cystectomy. Ejaculatory problems may be experienced following total pelvic exenteration. This radical surgery removes all organs situated in the pelvis including the male genitalia with subsequent colostomy and urostomy.

Treatment effects on female sexual function
Health professionals often perceive pre-treatment discussion of sexual function among females as a low priority. Conversely, the effect on male sexual function is usually recognised (Borwell, 1997). In females, radical rectal surgery may result in alteration of pelvic anatomy, causing coital difficulties such as scarring, difficulties with penetration and discomfort. Multiple problems are associated with pelvic irradiation, including vaginal stenosis and dryness. Management of these problems should include consideration of factors related to the pre-disposing condition. Some chemotherapeutic agents can increase vulnerability to vaginal infections, with resultant odour and reduction in self-esteem. Post-discharge there may be a reduction or cessation of previous sexual activity due to psychological issues related to body image and reduced sexual attractiveness.

Successful pregnancies are possible after some treatment, dependent on fertility status and surgical technique. When assessing pre-menopausal women contraceptive and pre-conceptual advice should be given.

Assumptions must not be made that existence of a medical problem eradicates sexual needs. Preliminary assessment should determine any sexual dysfunctional problems pertinent to other medical or surgical conditions, including the degree of sexual satisfaction currently experienced. Existing disturbance in sexual function could be biological, physiological or neurological in nature, affecting sexual response and the concept of body image and QOL for either sex.

Discharge needs
Discharge preparation is central to care following major surgery and an integral part of the patient journey and rehabilitation. Considerable support is necessary and the involvement of carers is acknowledged, but often overlooked. Powerful feelings and emotions often associated with anxiety, anger, and insecurity away from the safety of the hospital environment, can affect individual behaviour toward adaptation of bodily changes. This can be compounded by physical weakness and lethargy following a debilitating condition and major surgery. Established social support networks offer the surroundings where a normal body image is shaped and an altered body image is integrated into society (Price, 1989). The experiences associated with a stoma can be profound, irrespective of a patient's previous role and status in life. Continuity of care from stoma care nurse specialist and liaison with community health care professionals can care the transition from hospital to home (Wade, 1989).

The needs are often ongoing, and are not just short term needs post-discharge. Rehabilitative care is ongoing, sustaining the therapeutic relationship helps to further restore confidence and self-esteem with considerable benefits on wellbeing. This can involve continuing community and
hospital liaison with the patient, the involvement of social and peer support networks, contact with a specialist nurse, and, if required, psychosexual counselling.

**Education**

Recent research in rehabilitation care reports a resistance from health-care professionals to integrating the topic of sexuality into their work, in spite of the acknowledgement that patients with sexual problems will be encountered (Gannon et al., 2006). It is vital that nurses take advantage of opportunities to explore and debate the sexual nature of patients’ relationships, in preparation for the sexual dilemmas they will encounter within practice. This will enable them to respond thoughtfully in an informed and rational manner, avoiding panic, distress and destruction.

**Psychosexual awareness**

Facilitating the integration of sexual wellbeing in nursing and health-care practice involves developing psychosexual awareness skills to assess and understand individual circumstances. Ways in which this can be done include providing health-care professionals with:

- Sexual education in respect of changes incurred through the normal biological and physiological processes, such as aging.
- Education relating to changes associated with disease, and the treatment of medical conditions.
- Education relating to the taking of sexual history and the discussion of patient issues. This appears to facilitate the integration of sexuality into nursing and health-care practice and forms an essential part of holistic care.
- Information dispelling the myths associated with chronic/mental illness and sex.
- Effective communication and counselling skills.
- Encouragement to reflect on patient sexual wellbeing, and its impact on rehabilitation.

Inter-professional working, essential, be this multidisciplinary or interdisciplinary, focusing on goals identified by the individual patient. Importantly, team members should establish which categories require consideration in relation to the goals identified by the patient, and of those, which they feel most comfortable working on. Conducting a personal and reflective analysis provides nurses with an objective review of their current level of skills and expertise.

A nurse can carry out such a review by:

- Listing strengths, detailing which aspects of psychosexual awareness and helping skills they feel confident with.
- Listing weaknesses, considering which areas need further training or knowledge to help improve their performance.
- Considering what opportunities and resources are available to help them develop further knowledge, skills and competence.
- Considering what could be the obstacles or restrictions limiting this aspect of personal development – could it be difficulty in accessing further training or inappropriate training to fulfil personal development needs.

Having undertaken this analysis a personal, reflective action plan can be written, using the reflective cycle (Graham, 1998) (*Figure 1*) as a structure. At the preparatory phase, the health-care professional considers the demands of the experience and the potential resources required. The experiential phase is when practice occurs. The processing phase is the clarifying of the experience of the preceding event of interaction. The outcome of this experience is changed contextual perspectives. Evaluation and review occur at the end of each phase.

**A framework for assessment**

Whilst all health-care professionals should have a basic understanding of sexuality and sexual changes throughout the lifespan, some interventions require higher levels of knowledge and skills. One example of an intervention is communication about issues and circumstances that may have an effect on sexuality due to treatment or medication. Another is the taking of appropriate action such as referral to a more suitable health-care professional, or to additional information, knowledge or resources and services. By using a framework and reflection the practitioner is allowed to function at differing levels of psychosexual care.

**The PLISSIT Model of Sexual Health Intervention**

Permission, Understanding-Limited Information, Specific Suggestions, Intensive Therapy (PLISSIT) (Anon., 1976) model offers four levels of counselling, and encourages nurses to intervene at the level at which they feel most comfortable.

**Permission (the beginning, listening or exploratory stage)**

Patients with actual or potential sexual concerns or issues relating to their medical condition may need either permission to acknowledge they need help to discuss sex, or the respect of who and what they are, to be able to own their complex feelings. Active detection of sexual concerns is important for any patient, and requires the nurse to be sensitive and use active listening skills. This not only gives patients permission to discuss the topic of sex, but also seeks consent to explore intimate issues. Interest shown by the health-care professional can alleviate concerns. Having broached the topic of sex, an assessment based on patient expressed concerns can be conducted.

*Figure 1. The reflective cycle*
Understanding-Limited Information
Facilitating conversation on information already acquired enables the health-care professional to assess what difficulties (if any) are being experienced. For example, patients with long-standing gastrointestinal problems may have existing fears about bowel control due to diarrhoea or anal sphincter failure, thus inhibiting developing sexual relationships and sexual performance. As well as taking a sexual history, the problems, goals, and expectations of the client need to be identified and an action plan devised, enabling the health-care professional to establish if more specialist help is required, or further discussion and counselling.

Specific Suggestions
This is the action stage, where the health-care professional will be giving reassurance, bearing in mind that some patients will need more than permission and information. To operate at this level the health-care professional requires additional knowledge and skill (RCN, 2000). The specific suggestions do not only relate to sexual behaviour – every feature of sexual wellbeing should be addressed. Suggestions might include providing written information about sexuality and illness, or pouch emptying before sexual activity. Some couples may require relationship counselling in addition to sexual counselling.

Intensive Therapy
This is a behavioural-based action stage. This advanced stage may require specialist involvement to address multifaceted interpersonal and psychological issues, and possible physical needs (RCN, 2000). Some patients might need help from an urologist or gynaecologist, others may require specific, systemic, behavioural programmes designed to change sexual behaviour and function. The skills of a recognised sex therapist who can offer intensive therapy tailored to individual needs may be required. Health-care professionals should be knowledgeable of appropriate resources and have referral abilities (Anon, 1976).

From PLISSIT to EX-PLISSIT
Davis and Taylor (2006) describe EX-PLISSIT as an extension of the original model. The literature states that the four stages of PLISSIT are interconnected and propose each phase is conducted in a linear manner. Health-care professionals may feel 'sexual wellbeing' has been addressed once Limited Information has been discussed, but this should be questioned. For example, a patient with long-standing gastrointestinal problems had a surgical repair for faecal incontinence – has confidence and control been restored to enable resumption of sexual activity?

Davis and Taylor emphasise the flexibility of interconnection in the EX-PLISSIT model by endorsing a comprehensive learning cycle of reflection and review, thus challenging assumptions in order to promote self-awareness.

Conclusion
Patients with a stoma face significant changes to their recognised body image, sexuality and existence. They encounter many losses due to their changed physical appearance and altered bowel/urological function. Psychological adaptation and successful rehabilitation following surgery are potentially achievable by comprehensive assessment, facilitating further understanding of individual patient, family and community needs. Adopting an integrated approach to rehabilitative stoma care will enable the health-care professional to utilise specialist expertise of other health-care professionals. This will enable health-care professionals to offer care that is participative, collaborative and empowering, and can promote a positive patient outcome.

Royal College of Nursing (2000) Sexuality and Sexual Health in Nursing Practice. RCN, London

KEY POINTS
- Rehabilitative stoma care requires a multi-professional approach.
- Stoma care nurses play a pivotal role in psychological adjustment.
- Discussion and education on psychosocial wellbeing should be included in the many topics covered by the health-care professional.
- Support from family/relatives is significant for effective rehabilitation.