Psychological consequences of malignant melanoma: patients’ experiences and preferences


Summary

This article reports on the findings of a literature review exploring the psychological impact of malignant melanoma on patients, from diagnosis to follow-up. It examines the preferences expressed by patients with regard to ongoing support from nurses in this field, and draws attention to some implications for practice. A small but significant body of literature provides information on the psychological stress experienced by patients with melanoma, and on their coping strategies. Preferences are expressed on the way that information is given at diagnosis and the support offered by the healthcare team during diagnosis and at later consultations. These preferences and experiences have implications for nurses working in cancer care in general, and skin cancer in particular.

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It is the aim of this article to review the literature in this field, following the patient from diagnosis, through treatment to follow up. The lived experiences of this group of patients and the effect on their psychological wellbeing has led to the expression of certain preferences for the support they receive from the healthcare team, and in particular nurses; these will also be discussed.

Literature search methodology

Most of the literature on malignant melanoma focuses on causes, prevention and treatment. Research examining the psychological impact of a cancer diagnosis rarely looks solely at melanoma, although a few such articles exist. There is also little work on the effect of nursing intervention on patient experiences.

A number of methods were used to access the relevant literature. Several databases were searched: CINAHL (Cumulative Index to Nursing and Allied Health Literature); British Nursing Index; Medline; and PubMed. The search terms used to access articles were: melanoma and psychological support; melanoma and nurse; skin cancer and nurse; and cancer and bad news.

Search limits were set initially at 1998–2005, a lack of relevant material necessitated this broad time frame. The search excluded non-English text articles, but included articles from northern Europe, North America and Australia, because work in the area of psychological support for patients with melanoma and informational needs of patients with cancer in general is more extensive in these countries. After reading through this material, and further hand-searching of nursing and medical journals, particularly in the areas of dermatology and oncology, articles were accessed by ‘backward chaining’, that is, following up the references from a pertinent article, further lengthening the time frame for articles with particular relevance where there was no corresponding recent study available.

MALIGNANT MELANOMA is a potentially fatal skin cancer that is rapidly increasing in incidence in the UK (Cancer Research UK 2006). For the majority of patients treatment involves surgery as a day case under the care of a dermatologist or a plastic surgeon, without further tests or adjuvant therapies (Roberts et al 2002). The likely psychological effects of diagnosis on patients with malignant melanoma has been under-explored in the past, and the resources available for emotional, informational and social support have lagged behind those provided for other cancer patient groups (Hancock 2003, Nursing Times 2005).
From the review it was decided to focus on the information that exists on the preferences and experiences of patients with malignant melanoma using three main themes:

- Diagnosis: becoming informed.
- Coping: living through treatment and follow up.
- Nursing support.

These themes were used to group similar ideas that appeared in different articles, therefore they were only implicitly consistent.

**Diagnosis: becoming informed**

Recommended methods of breaking bad news have been developed and widely adopted (Buckman 1992, Faulkner 1998, Schofield et al 2001, Higgins 2002). These include guidelines on the personnel who should be involved, environment and forms of information, as well as advice on the style of words to use and helpful behaviours to adopt. Dowsett et al (2000) note that most guidelines written for breaking bad news are based on clinical opinion, rather than patient preference.

**Information needs**

To assess fully the experiences and viewpoint of patients it is appropriate to use a qualitative approach, as demonstrated by Winterbottom and Harcourt (2004). In a phenomenological design these researchers conducted semi-structured interviews exploring the experiences of 16 patients with skin cancer, mapping their journey from discovery of a skin lesion through to referral and treatment. One of the most common themes with implications for practice was a failure to meet information needs fully. Patients responded positively to specific, well-explained information about diagnosis and prognosis.

Using in-depth interviews with 17 patients from a UK cancer centre, Leydon et al (2000) explored why patients do not always seek out information beyond that volunteered by the doctor during a consultation. They identified three themes: faith (in the doctors, precluding the need to know more); hope (the need to remain positive and use the term ‘cancer’ had no effect on depression scores in the long term. In general, it appears that patients want open, honest discussions about their diagnosis, prognosis and treatment options, with emphasis on the positive aspects of their prognosis wherever possible.

**Psychological impact**

Expressing shock at diagnosis is common among patients with malignant melanoma. The shock was of a different type to that experienced by patients with non-visible cancer. For example, Winterbottom and Harcourt (2004), Taylor (2004) and Wheelhouse (2004) all cite examples of interviews with patients who found the initial diagnosis shocking and distressing, particularly as several had been ‘living with’ a changing mole for some time, and now had to deal with the knowledge that something could have been done sooner had they been ‘living with’ a changing mole for some time.

Using in-depth interviews with 17 patients from a UK cancer centre, Jenkins et al (2001) used a questionnaire in a descriptive quantitative study to find out cancer patients’ information preferences. Eighty-seven per cent of the patients (n=2,331) wanted as much specific information as possible, both bad news and good. These results have been reinforced by Schofield et al (2001) who studied newly diagnosed patients with malignant melanoma, and Hagerty et al (2005) who concentrated on patients with incurable metastatic cancer, including malignant melanoma. Schofield et al (2001) found that using the term ‘cancer’ had no effect on depression scores in the long term. In general, it appears that patients want open, honest discussions about their diagnosis, prognosis and treatment options, with emphasis on the positive aspects of their prognosis wherever possible.

**Recommended methods of breaking bad news**

A descriptive survey of 131 patients with malignant melanoma approximately four months after diagnosis formed the basis of work carried out by Schofield et al (2001), which compared the preferences of their sample with the Australian recommendations on breaking bad news. Sixty two per cent of patients ranked ‘being told face-to-face’ as the most important feature of communication, with ‘feeling confident that they are getting the best treatment’ rated next.

This latter feature may be especially prominent in patients with malignant melanoma, for whom surgery is the only recommended
treatment. Many may be expecting follow-up chemotherapy or radiotherapy, but this is not indicated for a primary melanoma cancer (Roberts et al 2002). Most of the available literature indicates that this sort of specific information should be freely shared with these patients, together with time for questions and an empathic approach that encourages the patient to participate fully in formulating a plan of care.

The question of whether to have a nurse or other healthcare worker present at the time the patient is told the diagnosis has been examined repeatedly in the literature. Schofield et al (2001) found that most of the patients with malignant melanoma did not rate this option highly enough to endorse it as a priority for healthcare teams. Their questionnaire asked participants to choose from options of who they would have liked to be present at diagnosis. Predictably, many chose ‘spouse’ (44 per cent), and ‘no-one’ also scored highly (47 per cent), with no votes for ‘nurse’ or ‘social worker’. In addition, 73 per cent wanted to talk to a counsellor at some time afterwards, suggesting that listening skills and emotional support would be valued if offered by a healthcare professional.

In a more recent article, Schofield et al (2003) used the same data as in 2001 to explore the communication strategies best designed to optimise patient wellbeing. They commented that there were not enough instances of a nurse being present at the time of diagnosis—giving for these patients to judge any positive or negative effects. Their findings are reinforced by Parker et al (2001) and Hagerty et al (2005), who found a low preference rating for having another healthcare worker present to offer support; but in all three studies the question raised with the participants gave no indication of what a nurse or other might do if present.

**Coping: living through treatment and follow up**

**Early days** One of the first questions that patients with malignant melanoma may ask, as is the case with all cancer patients, is ‘how did I come to get this?’ The links between sun exposure, skin type and melanoma incidence are proven (Roberts et al 2002), and any answer to patients on this point will implicate their behaviour as the cause and emphasise the need for change.

In a qualitative study of 11 men with malignant melanoma, Taylor (2004) noted that gender played a part in the sun behaviour of the participants, both pre and post-diagnosis. Some patients had avoided the initial consultation, not wanting to take time off work, or to ‘bother’ the doctor unnecessarily despite suspecting that there might be something wrong; and some men were reluctant to change their habits with respect to sun exposure, self-examination and seeking medical advice. She found that trivialisation (downplaying the significance of their condition) and normalisation (denying symptoms to maintain normal social interaction) were common coping mechanisms in this group.

Butow et al (1999) reported a range of commonly used coping strategies among patients with malignant melanoma, which fell into three broad categories: active (seeking out information), distractive (trying to forget) and avoidant (for example, drug-taking). In their qualitative study, Winterbottom and Harcourt (2004) found a variety of coping strategies exhibited by this group of patients, and highlighted other individual methods of coping such as avoidance of information, comparison with others, and personal faith.

These articles give a different picture to the widely cited work of Cassileth et al (1982), who used a self-report questionnaire to measure psychological status in a number of dermatology patient groups. Patients with malignant melanoma showed less anxiety and depression, and significantly higher scores for wellbeing than patients with chronic skin conditions such as acne and psoriasis that tend to lower self-esteem. The Mental Health Index of the General Well-Being Scale is the data collection tool used by Cassileth et al (1982). It is validated by, among others, the United States Center for Health Statistics (National Center for Health Statistics 1977). However, the patients sampled were all newly diagnosed with malignant melanoma and were hence ‘coming to terms’ with a changed situation involving a life-threatening illness; the other dermatology patients had all had to live with a chronic condition for some time. This suggests a possible bias in the sampling technique, and a failure to compare like for like. Cassileth et al (1982) suggest that self-esteem may be enhanced by the process of dealing with a difficult diagnosis, as patients find themselves coping with a potentially life-threatening disease and dealing with all the related physical, emotional and social demands; but they do not suggest how true this may be in the long term.

A longitudinal study by Brandberg et al (1993) compared patients with a better prognosis and those with a less favourable prognosis, and found no psychological differences between them except for more sleeping difficulties in the latter group. In her review of the literature, Boyle (2003) noted that patients with early-stage malignant melanoma...
experience long-term recurrent anxiety, again emphasising the significant psychological impact that this disease can have even when the prognosis is good.

**Ongoing issues** Since malignant melanoma has the capacity to metastasise at any point following treatment it is vital that follow up involves disease surveillance, both by healthcare staff and by patient education to promote self-monitoring (National Institute for Clinical Excellence (NICE) 2005). The psychological impact on those patients who go on to experience metastatic disease can be devastating, and it is beyond the scope of this article to discuss that further.

For the majority of patients, follow up involves regular health checks in a secondary care setting, as well as advice on self-examination and sun protection, usually given by a specialist nurse (Beckford-Ball 2005). Boyle (2003) emphasises the important role that follow-up clinics play in promoting emotional wellbeing. This view is supported by Dancey et al (2005), who surveyed 231 patients with malignant melanoma and reported that 98 per cent found follow-up clinics useful and reassuring.

On the issue of skin self-examination, Phelan et al (2003) comment that patients with melanoma can experience difficulties in recalling the appearance of their own skin, heightening their anxiety regarding possible sinister changes. Beckford-Ball (2005) also notes that any form of follow-up care can prevent some patients from feeling that life has got back to normal.

**Nursing support**

In *The NHS Cancer Plan* (Department of Health 2000), the government identified the need for specialist cancer nurses to take on new responsibilities in education, advice and support, bringing dermatology cancer care into line with other oncology provision.

In a simple descriptive analysis of three melanoma case studies, Wheelhouse (2004) took data from several sources, including the patients, and reflected on implications for practice. She noted that the absence of a nurse to co-ordinate the patient’s care pathway resulted in the patient feeling more anxious than necessary. Conversely, the experience of a patient with melanoma whose care pathway was managed by a clinical nurse specialist for skin cancer highlighted the positive role played by the nurse in meeting information needs and offering psychological support. These findings are supported by Winterbottom and Harcourt (2004), who note that patients with malignant melanoma appear to use a wide range of coping strategies and some patients may require additional nursing support to help them to cope, both at diagnosis and beyond.

The work cited earlier by Schofield *et al* (2001) did not endorse the practice of having a nurse present at diagnosis-giving. However, as they stated in a later article (Schofield *et al* 2003), their sample did not include enough patients with experience of nursing support to reach this conclusion. While initial communication of a cancer diagnosis usually falls within the remit of the doctor, there is often need for reiteration or expansion, and nurses are frequently put in the position of sharing information with patients and relatives.

Being present at diagnosis-giving allows the nurse into the process, and he or she may become a consistent contact for the patient (Dunniece and Slevin 2000, Hancock 2003) and support patients throughout the period of coming to terms with bad news. Faulkner (1998) notes the importance of defining roles in the multidisciplinary team. Morton (1996) advocates properly trained nurses being involved in the ongoing process of breaking bad news and sharing information, once the initial diagnosis is made. Patients with malignant melanoma require information about diagnosis, prognosis and treatments and practical help such as financial advice, all of which a nurse can offer either directly or through referral to appropriate services (Hancock 2003).

**Conclusion**

There is a significant body of work that examines the preferences and experiences of cancer patients, although studies focusing solely on the experiences of patients with melanoma are few. While the body of qualitative literature on the lived experiences of patients with malignant melanoma is small, it gives an important insight into the needs and preferences of this group of patients throughout the care pathway.

Melanoma, in common with other cancers, has a significant psychological effect on patients at initial diagnosis and beyond (Butow *et al* 1999, Wheelhouse 2004). This impact does not necessarily correlate with the severity of the prognosis (Brandberg *et al* 1995, Boyle 2003). The visible nature of the cancer seems to play a part, with patients expressing anger that they did not recognise the need to modify behaviour or seek treatment sooner (Winterbottom and Harcourt 2004, Taylor 2004).

Prognosis, individual factors and gender all play a part in a patient’s ability to cope with a diagnosis of malignant melanoma. However, patients with melanoma respond positively to clear, honest information about diagnosis and prognosis, and to being involved in the treatment plan.

Investigating the experiences of patients with melanoma gives insight into a broad range of
coping strategies (Butow et al 1999, Winterbottom and Harcourt 2004). Generally, these patients favour the input of a regular follow-up service, finding health surveillance and education helpful in alleviating anxieties (Boyle 2003, Dancey et al 2005).

Some literature casts doubt on the appropriateness of the nurse as support at diagnosis-giving (Parker et al 2001, Schofield et al 2001, Hagerty et al 2005). However, patients with melanoma use a range of coping strategies that may be assisted by the ongoing practical and psychological support of a healthcare professional.

There is strong support for the role of a designated nurse being involved in the care of patients with malignant melanoma to reinforce information, give specific advice and education and provide emotional support both at diagnosis and throughout the ongoing follow-up process (Winterbottom and Harcourt 2004, Wheelhouse 2004, Dancey et al 2005).

References


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