London Cancer

Psychosocial Support For Adult Skin Cancer Patients

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1. Introduction

This London Cancer guideline should assist clinical leads and clinicians in skin cancer care in understanding what requirements there are for psychosocial support for skin cancer patients, appropriate referral pathways, assessment and intervention for psychosocial difficulties and other responsibilities of level 3 and level 4 psychosocial professionals.

This guideline is informed by the work of the Psychosocial Expert Reference Group and the Living with and Beyond Cancer Board of London Cancer and the National Cancer Peer Review Programme on psychological support measures.

2. A stepped care model to address psychosocial needs

NICE guidance (2004) proposed a 4 level stepped care model of how psychosocial support should be organised for cancer patients. A common goal across these levels of input is to enable a patient to adjust physically, emotionally and psychologically to the cancer and its treatment. The diagram below illustrates how many patients may have psychosocial needs and experience distress. In addition, distress levels can vary across time and either increase or decrease. Some of this need can be addressed by non-psychosocial professionals, with a minority requiring more specialist input. Information not specific to skin cancer suggests that in the first year following diagnosis 10% of patients access care at level 4, 15% at level 3 with a further 10% needing intensive level 2 input.

The volume of each portion of the pyramid represents the number of people who should access this level of psychosocial support.
3. Staffing requirements

Each professional that meets with a cancer patient can be instrumental in providing psychosocial support. Providing a compassionate environment in which people feel able to ask questions and eliciting a patient’s concerns are important foundations.

The skin cancer multi-disciplinary team should ensure that there is at least one professional with Level 2 training in advanced communication skills (a Peer Review requirement). Most commonly, clinical nurse specialists would complete such training though other professionals with patient contact can access this training too. As part of practice at level 2, there is an ongoing requirement for supervision of their work. This should be provided by an accredited supervisor. Within London Cancer, this takes the form of monthly Clinical Discussion Groups facilitated by a level 3 or 4 professional that is accredited to provide this type of supervision. Attendance is required at 75% of sessions.

The skin MDT must also be able to refer patients to both level 3 and level 4 professionals, where assessment has identified this. These professionals can be part of the skin MDT or may be part of the oncology service or specific departments (e.g. a psychologist working in plastic surgery or in a clinical health psychology department).

4. The psychosocial support pathway

A diagnosis of skin cancer does not mean that people have psychological problems. In fact, this view is unhelpful as it pathologises normal reactions (as a degree of distress is to be expected) and often fails to recognise resilience, a person’s capacity for self-management and their use of their own support mechanisms. At the same time, a patient’s presentation where they are quiet or upbeat does not suggest there may be no difficulties. While prognosis and cure rates associated with skin cancer lead to the assumption that skin cancer patients may have less to worry about than those with other types of cancer, research confirms that a proportion of skin cancer patients will experience significant difficulties, whether they have had a diagnosis of malignant melanoma (MM) or other skin cancers.

The prevalence rate of anxiety and depression is somewhere between 11-23% (Al-Shakhli et al, 2006; Brandberg et al., 1992; Kelly et al, 1995), with significant interference with daily life (Gibertini et al. 1992; Trask et al, 2001; Zabora et al, 2001). In fact, studies suggest that prevalence of clinically significant levels of distress are equivalent to that of breast and colon cancer patients and higher than for those with gynaecological and prostate cancer (Zabora et al., 2001). Identifying people with psychosocial needs is important but attention to the process of care is just as important since it predicts good clinical outcomes. For example, communication practices at time of diagnosis influence the degree of anxiety, depression and satisfaction with the care some 13 months later (Schofield et al., 2003).
Psychosocial support should also be available to carers and family if needed. There is little available research around carers or relatives specific to skin cancer. However, enlisting the cooperation of family, friends and carers and including them in the patient’s treatment, if this is acceptable to the patient, may offer us increased scope for supporting the patient. Patient and their relative or carer also influence each other and can affect engagement with or their views on treatment and the service.

Family, friends and carers can occupy different roles in relation to the patient. They can be a decision-maker, an advocate, a carer and much more. They may take on many administrative or instrumental tasks that were previously not their responsibility. They also often become a source of emotional support for the patient and help them engage in tasks to manage the disease. How well family, friends and carers negotiate a change in roles depends on their pre-existing relationship.

Family, friends and carers may occupy one or many of these roles voluntarily and feel able to manage both their own distress (if experienced) and help the patient. However, they themselves may be struggling in supporting their loved one or managing their own concerns and preoccupations. NICE guidance (2004) clearly highlights that they may have their own needs but could fail to recognise or share these with us as they often put the needs of the patient first. The guidance suggests that needs may also vary significantly depending on the time point of the patient’s journey and encourage us to acknowledge and assess these at crucial times points including diagnosis, end of first treatment phase, disease recurrence and terminal phase. This is because caregiver burden is usually affected by a patient’s prognosis, the stage of illness and the goals of their treatment or care. Assessment should be sensitive to the cultural and ethnic preferences of the social support around the patient.

While there are various interventions for caregivers, there is no specific evidence that would suggest one intervention may be more favourable or appropriate. Interventions include informational support, respite, offering massages, engaging caregivers in social networks and activities as well as one to one interventions that particularly focus on problem-solving.

4.1. Rationale for holistic needs assessment (HNA)

It may be helpful to know that the following factors are associated with increased vulnerability of distress, though none of them are reliable predictors of distress.

- **Demographic factors**: younger age, women, absence of committed partner, unemployment, lower education and economic adversity
- **Clinical factors**: greater deterioration, tumors on visible parts of the body, reduced physical quality of life
- **Psychosocial factors**: negative beliefs about skin cancer, passive/avoidant coping style, lack of social support, concerns about implications of skin cancer on self and others and mental health problems pre-existing the cancer diagnosis.
However, since there is no one way of identifying who will experience any particular needs requiring psychosocial intervention, routine HNAs ensure equity of access based on need. This is particularly important given the personal, service and economic costs associated with not addressing psychosocial needs (see below).

The responsibility for assessing psychosocial needs clearly lie with the service as patients may not articulate these concerns for a multitude of reasons, or even recognise them. HNA could therefore be a sensitive intervention to understand the difficulties a person is experiencing. London Cancer has agreed to a pan-London tool to complete HNA. Relevant staff (often but not exclusively CNSs) should be skilled in conducting these assessments and guidance is available for this, produced by London Cancer. Skills will be developed and consolidated via monthly clinical case discussion groups for Level 2 practitioners.

4.2. When to assess for psychosocial needs

Each point in a patient’s journey from diagnosis to interventions with a curative aim or transition to treatment with non-curative aims and palliation presents new challenges and concerns to the patient and significant others. This requires support and coping skills, with coping style mediating psychosocial and, at times, also clinical outcomes.

Therefore assessment of psychosocial needs should not be done once but repeated at significant time points (Barker et al., 2011). Depending on the specific cancer and treatment protocol, there will be variation in when assessments should take place. Knowledge of the pathway and clinical sensitivity should be applied in judging when to administer an HNA. At a local level, clinical nurse specialists and level 3 or 4 professionals should meet to further define this aspect of the pathway. Examples of important time points include:

(1) Initial diagnosis and diagnostic process

At diagnosis, patients with MM report significant reduction in emotional functioning, quality of life and greater fatigue and sleep problems (Al-Shakhli et al., 2006). This may include concerns about the prospect of surgery. 1 in 5 newly diagnosed non-metastatic melanoma patients reported some form of depression (Gibertini et al., 1992).

Prevalent emotions at the time of diagnosis include shock, feeling numb, disbelief, fear, anger, confusion, uncertainty, sadness, depression, despair, grief and anxiety.

Common behaviours that patients report or you may observe include sleep disturbance, appetite change, headaches, heart palpitations, social withdrawal or increased need to be around others, hypervigilance, delay in seeking treatment, altered interest in pleasurable activities, nausea and substance use.
(2) Treatment
Many skin cancers occur in the head and neck region with treatment involving an aspect of disfigurement. Patients expressed a wish for good cosmesis post-operatively (NICE 2006) from which we can infer concerns about changes in appearance. Research has been able to demonstrate that appearance concerns can lead to difficulties with social interactions (as people are often faced with questions, comments or staring), anxiety, depression and rumination, which a person often reports as “affecting their confidence” (Cassileth et al., 1983; Kneier et al., 2003; Rhee et al., 2003; Sollner et al., 1998). In addition, 1 in 4 MM patients beginning chemotherapy reported clinically relevant levels of anxiety (Sigurdardottir et al, 1993). In a recent study on psychological impact of split-thickness skin grafting it also found that appearance concerns, anxiety and low mood are present in a small but significant proportion of cancer patients (Hansen et al. 2012)

(3) Recovery, survival, recurrence and discharge from specialist service
Following treatment a person is often monitored with recurrence risk within 10 years of diagnosis. This continuous threat, as well as resuming previous activities, roles and responsibilities, requires positive adjustment. Psychosocial needs can be prevalent at this stage. For example, in a follow-up clinic of MM patients, where patients attended a routine follow-up at a pigmented lesion clinic, 54% reported a degree of anxiety, with 17% reporting physical symptoms known to be commonly associated with anxiety.

Patients may also be reluctant to be discharged from a specialist service, which if not indicated by other London Cancer guidelines, may be a good point in time to discuss a person’s psychosocial needs as this would suggest concerns about their ability to detect recurrence or anxiety around recurrence.

(4) Transition from curative to non-curative aims
Patients who have difficulty with adjustment at this point experience hopelessness, sadness and concerns about the future and uncertainty. Concerns may be about themselves as well as others. There are no studies available that are specific to skin cancer.

(5) Initiation of palliative care, death and bereavement

4.3. Decision on what level of care is appropriate for the patient
Following assessment clinicians should:

1) offer interventions, advice and support if it is within their skill set. If the person does not require level 3 or 4 input, but the clinician undertaking the HNA does not feel able to offer a level 2 intervention, they should identify a person able to provide the necessary interventions, advice and support as soon as possible

2) Where the needs are clearly psychological, referral to local support services will allow relevant specialists to determine whether level 3 or 4 input is appropriate.
4.4. Risk associated with non-use of psychosocial support services

There is some indication that clinical factors affect psychosocial functioning, for example that reduced physical quality of life has an impact on mood (Holland et al., 1999). However, other clinical parameters often do not have clear associations with the distress a person experiences. Conversely though, there is sufficient research demonstrating the impact of psychosocial factors on disease progression, relationships with health service professionals, coping and distress.

Patients with unmet psychosocial needs may delay seeking medical advice, have poor adherence to treatment and may not engage in post-treatment screening and preventative behaviours. This in turn involves a greater medical cost with increased rates of recurrence, morbidity and mortality.

Negative beliefs about skin cancer, particularly its impact on self and others, can affect engagement in care and lead to increased distress. This would make it difficult for professionals to recognise early or quickly any difficulties and act on the need for intervention. Therefore patients who frequently do not attend or have difficulty engaging should be of particular interest and engaging their wider support system may be an appropriate way of ascertain whether there is a need for psychosocial intervention. A passive or avoidant coping style also means that patients deal with stressors less well and therefore have poorer outcomes and increased distress. For example adaptive coping led to better adjustment (Fawzy et al., 1990a; Lehto et al, 2005) and a longer relapse free period (Brown et al. 2000; Fawzy et al. 1993; Rogentine et al, 1979).

5. Involvement of Level 3 and 4 professionals in routine care

Skin cancer teams may be interested in inviting level 3/4 professionals to routine processes within the cancer journey. Their involvement may be helpful in improving patient experience given their expertise at communication and relationships. Level 3/4 professionals could also be involved in helping the skin MDT work out how best to tailor patient education, particularly around how to engage those that may be less inclined to monitor their skin or seek help.

6. Quality assurance and governance

Research suggests that psychological interventions, which were provided to patients with MM, led to reduction in general mood disturbance, depression and anxiety (Bares et al., 2002; Boesen et al., 2005; Fawzy et al., 1990a; Fawzy et al., 1990b; Fawzy et al, 1993; Fawzy, 1995; Trask et al., 2003). Cost effectiveness (Bares et al., 2002) of interventions such as CBT have been demonstrated, leading to greater benefit (larger decreases in distress) than nursing staff dealing with distress driven calls.
Incorporation of HNA and outcome data from interventions into the MDM dataset may be useful for prompts and also audit purposes. This can look at best-evidence practice and drive any changes where necessary and also accumulate further evidence about the psychosocial needs of skin cancer patients and their response to psychological treatment.

Practitioners providing level 3/4 input should routinely collect outcome and experience data for patients offered treatment or high level support. This would help with quality assurance, gathering an evidence base for interventions provided and also produce data that can help non-psychosocial professionals understand the utility of these interventions in routine cancer care.
7. References


