

Psycho-Dermato-Oncology: Psychological Aspects of Skin Cancer

13

Andrew G. Affleck and Lesley Howells

The aims of this chapter are

- To describe the patient experience of being diagnosed and treated for skin cancer.
- To suggest ways to assess for distress and psychosocial morbidity.
- To describe the impact on the patient of breaking bad news and provide a best practice model.
- To describe the physical and emotional impact of treatments for skin cancer and the psychological support required.
- To illustrate with case studies specific psychological and emotional issues that may arise and their management with psychological interventions.

Introduction

Skin cancer has not received the same recognition as other types of cancer. Affected individuals may receive dismissive responses from others based on common misconceptions including: skin cancer only happens to people who sunbathe, skin cancer is rare, it can just be cut away, or it is not life threatening or serious. However, skin cancer is not rare and indeed is the commonest form of cancer; incidences are projected to rise by 7% annually. An individual's thoughts, feelings and behaviours form an integral and unique part of their illness experience. When treating a physical disease like skin cancer, busy health care professionals may overlook assessing

A. G. Affleck (⊠)

Department of Dermatology, Ninewells Hospital and Medical School, Dundee, UK e-mail: andrew.affleck@nhs.net

L. Howells

Maggie's Centres, London, UK

e-mail: Lesley. Howells@maggiescentres.org

and enquiring about the person's subjective experience. People developing a skin cancer form a diverse group with biomedical differences in tumour biology and so a spectrum of morbidity and mortality risk as well as other inter-individual differences that influence their experience and ability to cope (Winterbottom and Harcourt 2004). Individuals with life-threatening tumours may cope better than individuals with biologically benign local skin tumours and so one cannot be judgemental. Most research has been done on melanoma, the commonest life-threatening skin cancer, the incidence of which continues to rise. However, the vast majority of skin cancers arise from keratinocytes to form either basal cell carcinomas and low-risk squamous cell carcinomas (non-melanoma skin cancer) — these types only invade the skin locally and are eradicated by surgical excision. More aggressive skin cancers are rare, but metastases can arise. It is important to give patients accurate clinical information to avoid disproportionate distress; the word 'carcinoma' or 'cancer' can lead to catastrophic thinking in some individuals even though an explanation of the localised nature of the tumour has been emphasised; in this regard, some clinicians prefer using alternative terms —e.g. basal cell epithelioma or indolent growth of epidermal origin.

The principle goals in the treatment of skin cancer are to treat primary cancer, prevent disease recurrence and promote long-term survival. Surgically, physical function is preserved as much as possible and aesthetic outcome optimised by good reconstructive technique. Another important objective that has been neglected is to actively take measures to minimise the patient's distress which can be considered "the 6th vital sign" (Holland and Wiesel 2017). Distress, in the context of skin cancer and skin cancer treatment, can be caused by multiple factors each of which can be managed (Table 13.1). Psycho-dermato-oncology may be defined as 'the assessment and management of distress, psychosocial, emotional and behavioural factors associated with the diagnosis of skin cancer and its treatment'.

The Patient Experience of Being Diagnosed and Treated for Skin Cancer

Distress can occur at any part of the patient's healthcare 'journey'—before diagnosis, after diagnosis, during surgery or other treatment and after treatment. People and their families faced with a sudden life change such as a serious skin cancer diagnosis may experience a series of intense traumatic emotions as they try and adjust to this new reality and attempt to cope with the new challenges cancer creates for relationships, their home and working life, their sense of self and the loss of the future they had assumed for themselves. Emotions can intensify or appear unexpectedly at critical times in the cancer journey, e.g. during the staging process at diagnosis, in preparation and response to potentially disfiguring surgery, at the end of treatment, during survivorship when the person encounters physical late effects and psychological hurdles as they try to regain a sense of normality, upon recurrence and when facing a terminal prognosis.

Table 13.1 Targets of psycho-oncological interventions

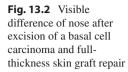
1. Physical symptoms
Pain
Fatigue
Sexual function
Insomnia
Cognitive disorders
Symptoms specifically related to cancer type/localisation or
form of treatment
2. Emotional problems
Psychiatric comorbidities
Fear of progression
Fear of local recurrence
Fear of new primary skin cancers
Other subthreshold psychological conditions, e.g.
demoralisation, irritable mood, hopelessness, health anxiety,
illness denial, fear of death
3. Assistance with practical/social problems
Return to work
Financial problems
Travel insurance
Life insurance
Child care
Housing
4. Family problems/support to caregivers
5. Spiritual aspects
Religious concerns
Meaning/personal growth
Death/bereavement
6. Improvement of general health
Lifestyle
Nutrition
Exercise
Stress management
Relaxation
7. Optimising treatment
Adherence to treatment (medical/surgical)
Treatment decisions
Use of analgesics
Use of alternative medicine

Surgery is almost always part of the treatment for skin cancer and a degree of stress is to be expected (Augustin et al. 1999). Tips to help reduce patient anxiety and make the experience as positive as possible during surgery have been described (Shenefelt 2010; Mitchell 2008). Larger surgical defects require more complex reconstructions. Most patients achieve satisfactory functional and aesthetic outcomes, although there are certain procedures that are more likely to result in

significant disfigurement, e.g. removal of whole or part of the nose (Moolenburgh et al. 2009), large excisions of the lip and 2 cm wide scar re-excisions for intermediate/thick melanoma often requiring split-thickness skin graft repair and partial amputation of an ear (Fig. 13.1). The use of a mirror to show the planned size of excision before surgery may help prepare a patient as can the use of clinical photographs of similar reconstructions to the one proposed. How closely the actual size of the scar matches pre-surgery expectations, is associated with the resultant emotional distress. Even smaller surgical excisions with apparent good aesthetic outcomes as judged objectively by the surgeon can cause the individual patient quite marked subjective distress. It is the patients' own perception of the outcome that is most important (Brown et al. 2010). The use of skin camouflage can improve

Fig. 13.1 Visible difference of ear secondary to partial amputation to excise a high-risk squamous cell carcinoma







aesthetic outcomes (Figs. 13.2 and 13.3). Caddick et al. (2012) studied psychological outcomes following surgical excision of facial skin cancer and found that although female and younger patients were more vulnerable to anxiety preoperatively, surgical excision of facial skin cancers improved social, emotional and cosmetic well-being. Rhee (2007) also found that the extent of disease was a factor in the quality of life scores. Lesions requiring less extensive reconstruction (e.g. direct closure) were associated with a more positive outlook. This might be explained by the patient's perception that less complex surgery meant less serious disease.

Adjustment to becoming visibly different, e.g. after cutaneous surgery, is a large topic and is reviewed in detail by Thompson and Kent (2001). The psychological impact of scarring includes disruption to activities of daily living; anxiety and depression; isolation; and altered body image (Brown et al. 2010) and cannot be assumed on the basis of age, gender, extent, severity or visibility of the disfigurement. Self-esteem is closely associated with body image and it is not surprising that patients with scars often report anger, frustration and low self-esteem. Chronic low-grade skin cancer precursors, e.g. actinic keratoses can cause a marked visible difference which can be upsetting to affected individuals (Fig. 13.4). Topical treatment with chemotherapy cream causes marked redness, which some people find embarrassing.

Fig. 13.3 Improvement of appearance and self-confidence with the use of skin camouflage

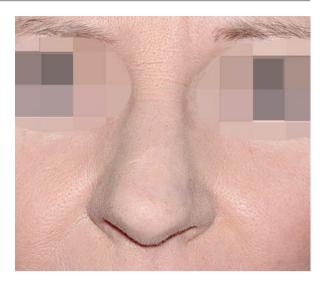
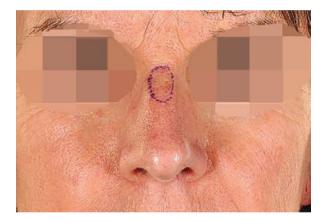


Fig. 13.4 Localised basal cell carcinoma on proximal nasal dorsum marked pre-surgery with catastrophic thinking that extensive subclinical spread is present and all the nose is involved



Winterbottom reported a qualitative study of 16 patients interviewed about their experiences of being diagnosed with skin cancer. Similar themes for melanoma and non-melanoma cancer were identified. Information and knowledge were key themes and influenced experience in different ways. People with melanoma used a wider range of strategies to cope with the diagnosis. Satisfaction with care experienced played a crucial role in minimising the adverse experience for the patients. Increased levels of anxiety were noted in patients who felt their diagnosis had not been explained with clarity. Patients often try to make sense of the disease trying to make a logical explanation as to what the cause might be. A common coping strategy that can enhance self-esteem involves trying to minimise the experience, using comparisons with others who are felt to be worse affected than themselves, comparing their

skin cancer with other serious cancers or diseases. Other coping styles include information seeking or indeed avoidance of information as well as using social support (Roberts et al. 2013). In some people changing behaviour helped them to adapt to the disease, e.g. in minimising sun tanning. Patients often tried to rationalise causes for the condition in an effort to make sense of the diagnosis as a way of restructuring their lives and also possibly to externalise any feelings of guilt that they may have.

Knowledge about patients' experience having skin cancer and different coping strategies enable health professionals to relate to patients better and have productive discussions. Specific concerns raised by patients can be addressed. Common reactions to the diagnosis of skin cancer include shock, fear, uncertainty, worry, guilt, helplessness, gratitude and resentment (Burden-Jones et al. 2010). The emotional impact in response to the challenges cancer brings may be overwhelming to some people; it compromises their ability to function on a day-to-day basis and affects their capacity to hear, retain, understand and act on information. Individuals may feel a loss of control, isolation and helplessness and may struggle with uncertainty, fears about their future and life expectancy. Positive outcomes include adopting a participatory stance, e.g. long-term improved sun-protective measures for self and the need to 'spread the word', advising others to use sunblock and avoid sunburning, a need to live life to the full, encouraging others to have any skin blemishes checked, more empathy towards others who have had cancer, increased awareness of skin with a lower threshold to have any new or changing skin lesion checked, and finding a positive meaning, e.g. deepening of friendships and relationships and coming to terms with their own mortality.

A sensible balance needs to be achieved and some patients initially (and a few continue long-term) adopt extreme measures which are disproportionate and unhelpful and so contribute to decreased life quality, e.g. some people stop going on sunny holidays, constantly checking skin, stopping previously enjoyed outdoor pursuits, and persistent guilty feelings for not having taken more care to protect skin from the sun. Hope, optimism and self-esteem should be maintained (Kneier).

Patients with advanced versus localised disease had more supportive care needs, particularly the amount, quality and timing of melanoma-related information, communication with and emotional support from clinicians (Dunn et al. 2017).

Rarely, an individual may feel pessimistic and without hope and develop depression and suicidal ideation. Completed suicide can arise after the diagnosis of a skin cancer; those with a poor prognosis, low survival rate and limited treatment options tend to be at the highest risk especially in the first 6 months after diagnosis (Wang et al. 2018).

Several different coping strategies exist—more than one may be used at one time and different strategies are used over time. Some strategies are considered better than others in promoting adjustment and reducing distress (Kasparian et al. 2009).

Fig. 13.5 Neglected deeply invasive ulcerated basal cell carcinoma on ear helical rim—cartilage has been destroyed by the tumour



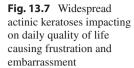
Maldaptive coping is associated with adjustment disorder and can be seen after skin cancer surgery. Denial of illness as a coping mechanism is not uncommon and can lead to neglect of a skin cancer with delay in treatment and so potential adverse outcomes (Flynn 2004) (Fig. 13.5). Catastrophic thinking is not uncommon in relation to fear of recurrence and concern regarding the size of the primary tumour (Figs. 13.6 and 13.7).

Most patients do cope and adjust overtime, putting the experience of having skin cancer behind them and continue with their lives without lasting psychological consequences. Qualitative studies examining patient narratives show common themes, for example, for the rare but life-threatening skin cancer Merkel Cell Carcinoma (Kaufman et al. 2018):

- Several tests and visits needed to establish the diagnosis
- Misdiagnosis
- · Lack of information
- · Growing painless lump
- · Shocked, scared by the diagnosis
- Unaffected daily routine and general physical condition
- Anxiety-related sleeping difficulties
- Fighting the disease
- Role of supportive relatives and friends
- Patients' experience with chemo and radiotherapy and expectations toward a study treatment in Merkel Cell Carcinoma
- Limited perceived efficacy of chemotherapy: success/relapse/failure
- Limited perceived efficacy of radiotherapy: success/relapse/failure
- Tolerability issues
- Disrupted activities
- Expectations towards the study treatment

Fig. 13.6 Healthy scar, left temple, 3 months after cutaneous surgery to excise a BCC. The patient was convinced that there was persistent tumour due to sensory symptoms consistent with neuropraxia causing 'stabbing pains'. A careful explanation and reassurance regarding wide excision margins helped her to understand the nature of her symptoms and spontaneous resolution occurred over the next 3 months







Psychological Intervention

The potential benefits of high-quality psychological care in a cancer setting are clear however, high-quality evidence is lacking (Peters 2012). About one in five people will be at least moderately distressed when diagnosed with skin cancer and among patients with malignant melanoma, the number is higher with one in three patients reporting clinically relevant levels of psychological distress in a systematic review (Kasparian et al. 2009).

With new treatments for metastatic disease, has come a more intensive clinical surveillance program for many high-risk patients, usually including imaging of asymptomatic patients, and this has increased the potential psychological burden. A systematic review of psycho-educational interventions for melanoma survivors identified four psychological intervention studies (amongst a total of 27 studies encompassing educational and psycho-educational interventions), and concluded that significant reductions could be achieved in common psychological symptoms including anxiety, depression and cancer-related distress (McLoone et al. 2013).

However, Dunn et al. (2017) reviewed qualitative and quantitative evidence for psychosocial outcomes for advanced (stage III/IV) melanoma patients. They concluded that high-quality trial evidence is still needed to clarify the impact of treatment innovations for advanced melanoma on patients' psychosocial wellbeing stating that 'Survivorship research and subsequent translation of that knowledge into programs and services currently lags behind gains in the medical treatment of advanced melanoma, a troubling circumstance that requires immediate and focused attention'.



Fig. 13.8 Holistic patient information leaflets on skin cancer produced by MacMillan

However, whilst awaiting trial evidence, health professionals can still improve their confidence and skills in talking with such patients who may be confused, scared and ashamed of their beliefs and feelings. Good relational skills are needed to help develop a therapeutic alliance with the patient. Effective communication is critical (Fallowfield and Jenkins 1999).

Generally, it is recommended that all patients who show distress, have low levels of social support and experience cancer-related difficulties in daily life, should be offered psychological support regardless of whether they have a diagnosed psychological disorder. The supply of relevant self-help materials can help some patients through the adjustment process, e.g. MacMillan cancer information booklets and online https://www.macmillan.org.uk/ (Fig. 13.8).

Psychosocial and Quality of Life Assessment

Routine screening for distress by the medical team is recommended to identify vulnerable patients and enable the effectiveness of psychosocial support to be enhanced by tailoring it to a person's current need. However, communication about psychosocial issues is delicate. There is evidence that many clinicians do not systematically inquire into the emotional problems of patients, and many clinicians prefer patients to bring up a problem.

On the other hand, patients may have trouble sharing emotional difficulties, and some do not want to address distress at all. A balance is required and an open invitation to patients to discuss matters if and when they wish is desirable. Distress is frequently not voluntarily disclosed to the person's medical team, so potentially alleviating psychosocial support is not provided. A baseline assessment of the patient's mood, ideas and expectations regarding their skin cancer and its treatment is desirable. Talking with patients about their experience and asking about specific concerns and emotional well-being should be routine practice. This empathic interaction is itself an essential element of an effective screening procedure. Screening for distress and difficulty coping related to skin cancer can be done using key questions, simple visual analogue scales and when needed, using other validated tools, e.g. include the 'Distress thermometer' (Cutillo et al. 2017), an ultra-short measure of psychological and practical distress; the Skin Cancer Index (SCI) (Rhee et al. 2007), a skin cancer-specific screening tool; the 'Hospital Anxiety and Depression Scale' (HADS) Zigmond and Snaith (1983) (Stern) which provides clinical cut off points.

A recent review recommended the use of the cancer-specific EORTC QLQ-C30, especially in late stages of disease, and the melanoma-specific FACT-M and skin cancer-specific SCI questionnaires as these instruments have been well validated and used in a number of studies (Chernyshov et al. 2019). Using a screening tool positively influences communications about psychosocial issues and distress.

Some degree of anxiety and stress is common in any individual having skin surgery; it would appear that only a minority are extremely anxious. Patients' desire for psychosocial support is an independent factor and may not correlate with high distress (Buchhold et al. 2016). Patient self-evaluation is an important instrument to identify patients who need psycho-oncological support (Mayer et al. 2017).

The commonest patient-reported reason for refusing psychosocial support services is that they feel no subjective need for such input. Broader reasons include; a preference for self-managing symptoms, not feeling distressed enough, a belief that their distress is not severe enough, a belief that help would be ineffective and receiving sufficient support from family and friends. Another important barrier is context-related when patients report they lack information about the availability of psychological support services.

Both a patient's desire for normalcy and their lack of information about the potential benefits of psycho-oncological treatment could lead patients to refuse psychosocial support. The subjective norms and information deficits of health care professionals also may influence the choice of patients to use psycho-oncological support services.

With a better understanding of the determinants and barriers along the distress screening pathway, access for underserved groups of distressed cancer patients can be increased and resources in psychosocial cancer care utilised efficiently leading to optimal management of patients.

NICE states that

- 1. 'During follow-up of patients treated for skin cancer there should be provision of psychological and emotional support to patient, carer and family'.
- 2. 'Those who are directly involved in treating patients should receive specific training in communication and breaking bad news. They have a responsibility for good communication with patients and carers'.
- 'Skin cancer patients should have access to psychological support services'.
- 4. 'There should have at least one skin cancer clinical nurse specialist (CNS) who will play a leading role in supporting patients and carers'.
- 'Skin cancer CNSs who have received training will be better equipped to identify and assist with the management of patients with psychosocial needs'.
- 6. 'All people with cancer should be offered access to timely and tailored psychosocial support'.

The nature and frequency of follow-up are influenced by the level of distress. Different levels of intervention can be provided by different NHS professionals and supportive care charities such as Maggie's Cancer Centres and Macmillan. Maggie has the advantage of offering all the NICE recommended levels of emotional, social and practical support under one roof adjacent to the NHS Cancer Centres and on a drop-in and more traditional referral basis (www.maggiescentres.org), (Lang-Rollin and Berberich 2018; National Institute for Health and Clinical Excellence 2006).

The NICE model emphasises the importance for all professionals involved in the person's treatment to appreciate their role in enhancing psychological wellbeing. In response to the challenges of cancer, people differ in their coping style, resilience to adversity and previous potentially debilitating life experience. Many people can be adequately supported through the crucial emphasis by their medical team on high-quality communication, through which concerns are elicited, listened to and acknowledged; bad news is delivered with empathy; complex information is offered in a paced and understandable form; anxieties displayed during surgical procedure are managed, and additional cancer support services (e.g. Maggie's) are signposted.

Screening and psycho-education are also within the remit and expertise of many MDT members. In particular the Clinical Nurse Specialists or Allied Health Professionals can assist in cancer-related problem solving, coaching in lifestyle change post-cancer (e.g. managing the risk of sun exposure) and guidance in the choice and use of psychological self-help materials and resources (e.g. Changing Faces as a support for coping with disfigurement). The medical team is also pivotal in collaborating with psychological specialists in the provision of Psychoeducational group support, particularly in the early stages after diagnosis when

personalised and understandable information is critical in managing anxiety and optimising a person's natural coping mechanism. Patients identified through screening or consultation as particularly vulnerable should be referred for prompt assessment by a psychological specialist (e.g. psychologist, psychiatrist either in the NHS or voluntary sector) to gauge the level of intervention required and determine whether psychotropic medication is indicated. Ideally, this specialist should work in close flexible liaison with the medical team. It is important to note that the level of psychological distress does not necessarily relate to perceived need for professional help, so patients may not seek or accept help even if it is indicated, therefore close monitoring and repeated recommendation is vital to ensure help is available when the person sees the need (e.g. the CNS monitors distress routinely at follow-up clinics).

Breaking Bad News

It is important to optimise initial discussions and engagement when giving a significant diagnosis. Having the person's partner present is helpful as is the provision of a written summary of the key facts and a contact details for a skin cancer clinical nurse specialist.

NICE guidance places particular emphasis on MDT members having training in Breaking Bad News. With its attention to empathy and inclusion of the patient, the SPIKES protocol has contributed immeasurably to professional practice (Baile et al. 2000). This seminal study is highly recommended reading material and is available free open access online at http://theoncologist.alphamedpress.org/content/5/4/302.full.pdf. However, Dean and Willis (2016) suggest that new evidence and changes in the context of care indicate several additions to the six steps of SPIKES.

SPIKES

Setting up the interview, assessing patient

Perception

Inviting patient to clarify how much they wish to be told
give Knowledge to the patient, address patient's

Emotions with empathic responses

Summarise the discussion and form a strategy for ongoing management

SPIKES is particularly notable for looking beyond breaking bad news as a single interview, the availability of multidisciplinary support for patient following the news and opportunity for the health professional to reflect on the emotional impact of having breaking bad news as a routine aspect of their clinical remit.

The PEWTER model also provides a useful mnemonic for defining a framework to communicate significant, life-changing news to a patient effectively (Keefe-Cooperman and Brady-Amoon 2013):

Prepare—Know what information will be presented and understand how to present it in clear language. Provide an unhurried and uninterrupted meeting with the person(s) receiving the difficult news.

Evaluate—Assess what the patient and family members already know or suspect and their present psychological and emotional status.

Warning—Give the patient an indication that serious news will be presented.

Telling—Give the information in a straightforward, nonapologetic calm manner in small pieces at a time. One should pause intermittently to confirm understanding prior to disclosing more information to ensure that the person is not overwhelmed.

Emotional response—Assess the person's reaction to the news and consider arranging another meeting for further discussion if necessary.

Regrouping preparation—Patient/doctor collaboration in response to the news emphasising realistic hope and aims for short and long term. Motivate engagement and identification of new goals.

Specific Forms of Psychosocial Support

It is seldom that a person will have a distinct diagnosable psychological disorder in response to their skin cancer diagnosis. Many cancer fears have a rational basis so traditional psychological approaches have been adapted for this population with an increasing evidence base supporting their effectiveness. The forms of support described are: Psycho-education Groups, and Cognitive Behaviour Therapy (CBT) Techniques, specifically 'Third Wave CBT' techniques which are particularly suited to physical health-related psychological problems. They include Mindfulness, Self-compassion and Acceptance and Commitment Therapy (ACT) (Hulbert-Williams et al. 2018). Most notably ACT techniques formed the key components of the CONQUER FEAR Trial (Butow et al. 2017). ACT is a trans-diagnostic form of

Cognitive Behaviour Therapy that enhances emotional self-regulation, the ability to live with uncertainty and the person's willingness to accept the irrevocable impact of their cancer. An integrative approach enables the therapist to develop specific tools from a range of theories that are often used within a core framework, including CBT and existentialism.

Melanoma survivors may benefit personally from sharing their cancer experience online and professionally facilitated support groups such survivor narratives can motivate behaviour change and facilitate coping among readers (Banerjee et al. 2018).

Psycho-Education

Open disclosure of negative feelings can be therapeutic. Normalisation of these feelings can help in patient adjustment. Psycho-education in individual and group format with people with skin cancer has been found to be acceptable and effective with both melanoma and non-melanoma skin cancers when particular emphasis is placed on building or fine-tuning active Problem-Focused Coping strategies and reducing avoidant coping strategies (Dieng et al. 2017).

Psycho-education is particularly successful in a group format, as the participants become a natural therapeutic support network, becoming role models for each other, exchanging experiences and empathising with each other's challenges. Ideally, the group is facilitated by a psychologist and CNS specialising in skin cancer. There is a different theme each week with open discussion and 'homework'. Handouts and online resources are utilised, and should be offered at key transition points in the cancer journey, for example, at diagnosis and when active treatment is completed. A brief, patient-centered psychological intervention in reducing fear of cancer recurrence comprising a 76-page psycho-educational resource and three individually-tailored, telephone-based sessions with a psychologist was found to have continued benefit 12-months post-intervention (Dieng et al. 2019a, b). The primary outcome was the level of self-reported fear of new or recurrent melanoma using the Severity subscale of the Fear of Cancer Recurrence Inventory (FCRI). Ideally, this type of implementation could be part of routine melanoma care (Kasparian et al. 2016).

Framework for Psycho-Education Group at Diagnosis

- Health Education specific to skin cancer diagnosis
- Stress management techniques (e.g. what is stress and why now? Relaxation, Mindfulness techniques and managing anxious thoughts)
- How to use Active Coping strategies and Problem Solving techniques (e.g. managing relationships at home, with work, with your medical team and GP)

As treatments become more successful in achieving remission and in managing cancer as a chronic illness, people have to cope with additional psychological, physical and practical challenges, for example, resuming work and family responsibilities that were 'shelved' during treatment; coping with late effects of their cancer

treatment and disfigurement; and navigating existential hurdles to find the means to invest fully in life knowing their life expectancy is limited. For many, cancer is also a catalysis for essential lifestyle change in exercise, nutrition and risk behaviours such as sun exposure. Psycho-education groups post-treatment are designed to assist people make the challenging transition between active treatment and building the life they want beyond cancer.

Framework for Psycho-Education Group at the End of Active Treatment

- Practical and experiential introduction to exercise, nutrition and stress management.
- Managing risk behaviour such as sun exposure.
- Cognitive behavioural therapy techniques to help live with uncertainty and fears
 of cancer recurrence and look afresh at work, home life and relationships and
 accommodate changed priorities.
- Training in how to build and utilise effective post-treatment partnerships with medical teams to enable smooth communication to enhance the monitoring of disease recurrence and late effects of treatment (Brown et al. 2019)

Cognitive Behavioural Therapy Based Techniques Including 'Third Wave' CBT

There is an established evidence base for the use of CBT, and increasingly, Third Wave CBT techniques in managing psychological problems associated with cancer when delivered by a Psychologist or accredited Mental Health professional (Hulbert-Williams et al. 2018). The goal of therapy is to help a person perceive their cancer and its irrevocable consequences adaptively; they haven't chosen to have cancer and its trajectory *but* they can choose how to respond and the extent to which it impacts on their life.

In the context of a non-judgemental therapeutic relationship, the patient is encouraged to:

- Connect with personal values as a compass to determine what matters to a person
 and how they wish to live their life, e.g. in relation to family, friends, work,
 health and leisure
- Explore how and why a person's psychological response to skin cancer (e.g. fear of recurrence) impacts on their ability to live the life that matters to them.
- Use psychological techniques and metaphor to help them become more self-aware, understand the psychological impact of their skin cancer and respond with greater psychological flexibility, so enabling them to stay connected to their values and live meaningfully despite the implication of their diagnosis. Psychological techniques include present moment awareness exercises, cognitive diffusion techniques, meditation and mindfulness activities for daily life, mindful movement (e.g. yoga), and self-compassion approaches.

 Develop a willingness to be more accepting of uncertainty and change; manage difficult intrusive thoughts, disturbing emotions and sensations; overcome avoidance and commit to living life more aligned with their values.

Case Histories

In this section four case studies will be used to illustrate the common and frequently overlapping forms of distress people experience and introduce the psychoeducational, and psychological therapy support that can be used.

1. Lisa's Story: Nurse-led individual psycho-educational support

Lisa was diagnosed and successfully treated for BCC associated with previous sunbed use. During a clinic appointment and two follow-up telephone calls, she forms a confiding relationship with her CNS. She describes her guilt and embarrassment about her diagnosis and her frustration with her family who are telling her to 'move on' before she feels she has processed the trauma of having had cancer. She identifies the opportunity to talk in confidence with someone outside her friends and family as central to her improved emotional wellbeing, together with advice about lifestyle changes.

2. Jen's Story: Psycho-educational group intervention

Jen is a housewife and child-minder in her late 50s with Malignant Melanoma. Her surgery was successful, but she could not receive adjuvant treatment due to a kidney transplant 12 years previously. In response to her diagnosis her mood immediately lowered, she became increasingly irritable and withdrawn. She took immediate and extended leave from her child-minding and gradually stopped activities that previously had given her a sense of accomplishment and pleasure. Her sleep was disturbed with panicky thoughts and agitated pacing. Her thinking was characterised by hopelessness, stating that she considered her life as now 'in limbo' until her eventual death. Jen was encouraged by her CNS to participate in psycho-education groups during and after her treatment to introduce her to others with similar fears, help her develop coping strategies to manage her emotions, particularly fear of recurrence and to build value into her life again by resuming pre-cancer activities that previously gave a sense of self worth. She also cultivated new activities such as a passion for exercise.

3. Sharon's Story: Individual psychological therapy for disfigurement

Sharon is a 40-year-old single Mum with a son in early adolescence. She has no support from the child's father, struggles financially and has recently been made redundant. A year ago she was diagnosed with Gorlin Syndrome for which she has since undergone three facial Mohs Surgery procedures. Her score on the Skin Cancer Index indicated significant distress associated with her perceived facial disfigurement and fears that her attractiveness will be further compromised by future surgery. She finds the relinquishing of control during surgery frightening and insists on being treated by a trusted surgeon. She obsessively checks for the sign of recurrence and ruminates through the day about potential

lesions. Fearing negative judgment from others, she has become socially isolated with a resultant lowering of mood and despite information to the contrary she fears her cancer will spread to other organs. Sharon was referred to a psychologist by her Consultant Dermatologist after routine screening for distress indicated her vulnerability.

A CBT for disfigurement approach was used. Initial concerns about the impact on attractiveness were addressed through questioning the validity of her self-appraisal and using evidence that contradicted her overarching belief that she was ugly. Resources from the charity 'Changing Faces' (www.changingfaces.org.uk) were pivotal in guiding therapy sessions. The aim was to help Sharon improve her confidence and manage her shameful thoughts around her scarring to overcome her social avoidance so she could live a valued life whilst coping with the often harsh societal norms for attractiveness.

4. Peter's story: individual psychological therapy for fear of recurrence and adjustment to terminal diagnosis

Peter is a senior manager in the public sector diagnosed with malignant melanoma that was initially treated with surgery and adjuvant chemotherapy. As a proud, stoical father of two children in their early teens, he saw his role as protecting his family and so did not disclose troubling thoughts and emotions. He used an avoidant coping strategy by distracting himself from difficult emotions without processing the significance of what he had come through and focused on 'getting back to normal' as quickly as possible. He returned to work without a phased return and resumed his fulltime responsibilities despite profound fatigue, sleeplessness, hypervigilance for any signs of recurrence, intense irritability and anxiety prior to routine monitoring appointments, daily graphic flashbacks to his chemotherapy and intrusive thoughts and images featuring a painful death. He would experience panic attacks when faced with making plans even for events only a few weeks in the future. When the avoidance of future planning became apparent to his manager he eventually sought help to deal with the psychological aftermath of his cancer treatment and uncertain prognosis. He was assessed as experiencing PTSD symptoms with associated fears of progression and depression. After Peter successfully developed strategies for alleviating and managing the symptoms of his PTSD and depression he returned to work and his wife was relieved by how he re-engaged in family life and planned the holidays that had been a valued feature of his pre-cancer life. Within 18 months he was found to have developed lung and brain metastasis and was given a very poor prognosis but also the chance to receive immunotherapy. He now had the task to prepare himself and his family for the uncertainty, physical and emotional impact of immunotherapy and the potential for death within a short timeframe.

Therapy for Peter at this stage was very typical of people on immunotherapy who live with uncertainty. He used 'Third wave CBT' including ACT and Mindfulness techniques to diffuse his troubling thoughts and focus on the 'here and now' through meditation. He read self-help literature, in particular, 'Facing the Storm, Using CBT, Mindfulness and Acceptance to build resilience when your world is falling apart' (Owen 2012) and 'The Reality Slap — How to find

fulfillment when life hurts' (Harris 2012). In the confidential setting of his psychology sessions he expressed extreme emotions (including anger, guilt, grief) and rehearsed conversations he wished to have with his wife. He was introduced to a weekly support group for people with metastatic cancer at his local Maggie's and gained hope through their lived experience that he could still live a meaningful life (Breitbart et al. 2018). He sought advice through Winston's Wish (www. winstonswish.org.uk), a charity to assist families when a parent has a terminal prognosis, and eventually he and his wife felt able to tell their children that although he was being treated successfully with immunotherapy, his condition was serious and ultimately life-limiting.

Practice Points

- Routine screening for distress is recommended for individuals diagnosed with a skin cancer.
- Clear communication of significant news (e.g. a new diagnosis of skin cancer) is recommended using best practice principles in breaking bad news and delivering complex information.
- Support using empathy and avoid making assumptions of emotional impact on the basis of disease severity. Always check for understanding of information provided but also the emotional impact of the information.
- 4. Help the person tap into existing resilience strategies and reach out where possible to family and friends for support.
- Liaison with colleagues in clinical psychology and psychiatry is indicated in individual cases.

References

Augustin M, Zschocke I, Godau N, et al. Skin surgery under local anesthesia leads to stress-induced alterations of psychological, physical, and immune functions. Dermatol Surg. 1999;25:868–71.

Baile WF, Buckman R, Lenzi R, et al. SPIKES - a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5:302–11.

Banerjee SC, D'Agostino TA, Gordon ML, et al. "It's not JUST skin Cancer": understanding their cancer experience from melanoma survivor narratives shared online. Health Commun. 2018;33:188–201.

Breitbart W, Pessin H, Rosenfeld B, et al. Individual meaning-centered psychotherapy for the treatment of psychological and existential distress: a randomized controlled trial in patients with advanced cancer. Cancer. 2018;124:3231–9.

Brown BC, McKenna SP, Solomon M, et al. The patient-reported impact of scars measure: development and validation. Plas Reconstr Surg. 2010;125:1439–49.

Brown L, Allan J, Makinson J, et al. Experiences of a cancer post-treatment group intervention and effects on reported well-being, worry, self-efficacy, diet, and activity. Psychooncology. 2019; https://doi.org/10.1002/pon.4994.

Buchhold B, Wiesmann U, Bahlmann J, et al. Psychosocial burden and desire for support in outpatients with skin cancer. J Dtsch Dermatol Ges. 2016;14:405–15.

- Burden-Jones D, Thomas P, Baker R. Quality of life issues in nonmetastatic skin cancer. Br J Dermatol. 2010;162:147–51.
- Butow PN, Turner J, Gilchrist J, et al. Randomized trial of conquer fear: a novel, theoretically based psychosocial intervention for fear of cancer recurrence. J Clin Oncol. 2017;20(35):4066–77.
- Caddick J, Stephenson J, Green L, et al. Psychological outcomes following surgical excision of facial skin cancers. J Plast Reconstr Aesthet Surg. 2012;65:e257–9.
- Chernyshov PV, Lallas A, Tomas-Aragones L, et al. Quality of life measurement in skin cancer patients: literature review and position paper of the European Academy of Dermatology and Venereology task forces on quality of life and patient oriented outcomes, melanoma and nonmelanoma skin. Cancer. 2019;33:816–27.
- Cutillo A, O'Hea E, Person S, et al. The distress thermometer: cut off points and clinical use. Oncol Nurs. 2017;44:329–36.
- Dean A, Willis S. The use of protocol in breaking bad news: evidence and ethos. Int J Palliat Nurs. 2016;22:265–71.
- Dieng M, Kasparian NA, Mireskandari S, et al. Psychoeducational intervention for people at high risk of developing another melanoma: a pilot randomised controlled trial. BMJ Open. 2017;7(10):e015195. https://doi.org/10.1136/bmjopen-2016-015195.
- Dieng M, Smit AK, Hersch J, et al. Patients' views about skin self-examination after treatment for localized melanoma. JAMA Dermatol. 2019a May 15; https://doi.org/10.1001/jamadermatol.2019.0434.
- Dieng M, Morton RL, Costa DSJ, et al. Benefits of a brief psychological intervention targeting fear of cancer recurrence in people at high risk of developing another melanoma: 12-month follow-up results of a randomised controlled trial. Br J Dermatol. 2019b Apr 9; https://doi.org/10.1111/bjd.17990.
- Dunn J, Watson M, Aitken JF, Hyde MK. Systematic review of psychosocial outcomes for patients with advanced melanoma. Psychonocology. 2017;26:1722–31.
- Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. Eur J Cancer. 1999;35:1592–7.
- Flynn TC. Denial of illness: basal cell carcinoma. Dermatol Surg. 2004;30:1343-4.
- Harris R. The reality slap. New York: Constable & Robinson Publishers; 2012.
- Holland JC, Wiesel TW. Principles of psycho-oncology. In: Bast RC, Hait WN, Kufe DW, Weichselbaum RR, Holland JF, Croce CM, Piccart-Gebart M, Wang H, Hong WK, Pollock RE, editors. Holland-Frei cancer medicine. Hoboken, NJ: Wiley; 2017.
- Hulbert-Williams N, Beatty JA, Dhillon L, et al. Psychological support for patients with cancer: evidence review and suggestions for future directions. Curr Opin Support Palliat. 2018;12:276–92.
- Kasparian NA, McLoone JK, Butow PN. Psychological responses and coping strategies among patients with malignant melanoma. Arch Dermatol. 2009;145:1415–27.
- Kasparian NA, Mireskandari S, Butow PN, et al. "Melanoma: questions and answers." Development and evaluation of a psycho-educational resource for people with a history of melanoma. Support Care Cancer. 2016;24:4849–59.
- Kaufman HL, Dias Barbosa C, Guillemin I, et al. Living with Merkel cell carcinoma (MCC): development of a conceptual model of MCC based on patient experiences. Patient. 2018;11:439–49.
- Keefe-Cooperman K, Brady-Amoon P. Breaking bad news in counselling: applying the PEWTER model in the school setting. J Creat Mental Health. 2013;8:265–77.
- Lang-Rollin I, Berberich G. Psycho-oncology. Dialogues Clin Neurosci. 2018;20:13–21.
- Mayer S, Teufel M, Schaeffeler N, et al. The need for psycho-oncological support for melanoma patients: central role of patients' self-evaluation. Medicine (Baltimore). 2017;96:e7987.
- McLoone J, Menzies S, Meiser B, Mann GJ, Kasparian NA. Psycho-educational interventions for melanoma survivors: a systematic review. Psychooncology. 2013;22:1444–56. https://doi. org/10.1002/pon.3165.
- Mitchell M. Conscious surgery: influence of the environment on patient anxiety. J Adv Nurs. 2008;64:261–71.

- Moolenburgh SE, Mureau MAM, Versnel SL, et al. The impact of nasal reconstruction following tumour resection on psychosocial functioning, a clinical-empirical exploration. Psycho-Oncology. 2009;18:747–75.
- National Institute for Health and Clinical Excellence. Guidance on cancer services. Improving outcomes for people with skin tumours including melanoma: the manual. London: NHS; 2006.
- Owen R. Facing the storm: using CBT, mindfulness and acceptance to build resilience when your world's falling apart. New York: Routledge; 2012.
- Peters EM. Psychological support of skin cancer patients. Br J Dermatol. 2012;167(Suppl 2):105–10.
- Rhee J, Matthews A, Neuberg M, et al. The skin cancer index: clinical responsiveness and predictors of quality of life. Laryngoscope. 2007;117:399–405.
- Roberts N, Czajkowska Z, Radiotis G, et al. Distress and coping strategies among patients with skin cancer. J Clin Psychol Med Settings. 2013;20:209–14.
- Shenefelt PD. Relaxation strategies for patients during dermatologic surgery. J Drugs Dermatol. 2010;9:795–9.
- Thompson A, Kent G. Adjusting to disfigurement: processes involved in dealing with being visibly different. Clin Psychol Rev. 2001;21:663–82.
- Wang SM, Cheng JC, Weng SC, et al. Risk of suicide within 1 year of cancer diagnosis. Int J Cancer. 2018;15:1986–93.
- Winterbottom A, Harcourt D. Patients' experience of the diagnosis and treatment of skin cancer. J Adv Nurs. 2004;48:226–33.
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67:361–70.