Patients’ experience of the diagnosis and treatment of skin cancer

Anna Winterbottom BSc MSc
Cancer Research UK, Psychosocial and Clinical Practice Research Group, St James’s University Hospital, Leeds, UK

Diana Harcourt BSc MSc PhD
Centre for Appearance Research, School of Psychology, University of the West of England, Bristol, UK

Submitted for publication 4 December 2003
Accepted for publication 24 February 2004

Correspondence:
Anna Winterbottom,
School of Psychology,
University of Leeds,
Leeds LS2 9JT,
UK.
E-mail: anna@winterbottom.co.uk

Purpose. This paper describes the experience of being diagnosed with skin cancer from the perspective of patients.

Background. Despite the number of people with newly-diagnosed skin cancer increasing each year, the psychological impact of receiving such a diagnosis has received little attention. Research in this area is sporadic and has predominantly focused on malignant melanoma and used a quantitative approach.

Method. Sixteen patients were interviewed about their experiences of being diagnosed with malignant melanoma, basal cell carcinoma or squamous cell carcinoma. The interview transcripts were analysed using thematic content analysis.

Findings. Similar themes for the two non-melanoma forms of skin cancer patients emerged. Information and knowledge of skin cancer appeared as a key theme, and influenced experiences in a variety of different ways. Patients with malignant melanoma recounted similar experiences to those with basal cell carcinoma or squamous cell carcinoma. People with malignant melanoma, however, used a wider variety of strategies in order to cope with the diagnosis. Satisfaction with the care experienced by each of the three groups played a crucial role in minimizing the experience for the patients.

Conclusions. Patients with skin cancer should not be conceived as a homogeneous group, but one in which there are a number of diagnoses which differ in prognosis, and so may result in a variety of different consequences and thus experiences for patients.

Keywords: nursing, skin cancer, qualitative, malignant melanoma, patients’ experience

Introduction

In 1998 over 38,000 cases of malignant melanoma (MM) were reported in the European Union (Ferlay et al. 1998). Accurate statistics for non-melanoma skin cancers are more difficult to obtain, although Cancer Research UK (2004) reported approximately 69,000 cases in the United Kingdom (UK) alone. There is a clear geographical pattern of increased incidence in those countries whose populations have predominantly pale complexions (Black et al. 1997). Whilst Australia claims the highest incidence rates in the world, it has become the commonest form of malignancy in the United States of America (USA). Indeed the prevalence of MM is increasing at a rate that is greater than any other type of cancer (Brooks et al. 2001). However, despite these statistics, the psychological impact of receiving a diagnosis of this type of cancer has received limited attention.
The three most commonly diagnosed types of skin cancer are MM, basal cell carcinoma (BCC) and squamous cell carcinoma (SCC). Although approximately 10% of skin cancer cases are MMs, the disease is ultimately responsible for the deaths of 50% of diagnosed individuals, claiming around 1600 lives each year in the UK (Cancer Research UK 2004).

Whilst the existing research provides some evidence of the experience of having skin cancer, work in this field has been sporadic and somewhat inconclusive. Most of the previous research has been quantitative and has focused only on MM. There is little literature on the experience of living through a skin cancer diagnosis, which may involve surgery and further treatment and may or may not be life-threatening.

**Background**

Because the condition is believed to be 80% preventable (Cancer Research Campaign 1995), protection against skin cancer relies to some extent on sun protective behaviour, such as using suntan lotion, and staying out of the midday sun. Research in this area has also examined individual intentions, attitudes and behaviour in relation to sunbathing and sun protective behaviours (Rodrique 1996, Jackson & Aiken 2001). The visible nature of the disease, and types of treatments available, have meant that patients are often left with scars and obvious disfigurement. It has also meant that there is a certain amount of reliance upon individuals to recognize the signs of skin cancer, such as moles changing shape and colour. Much existing research, therefore, places emphasis on seeking medical help or attending screening programmes (Artthey & Clarke 1995, Bergenmar et al. 1997). This necessity to recognize potential skin cancers is further reinforced by the fact that survival rates for MM are good if it is treated early. Cancer Research Campaign (1995) quotes statistics of a greater than 90% 5 year survival rate for patients who are treated with tumours of less than 1.5 mm thickness.

**Literature review**

Most of the limited research has focused predominantly on people with MM; on reactions to the diagnosis and quality of life issues (Kelly et al. 1995, Trask et al. 2001), anxiety and depression (Brandenburg et al. 1992), and coping during the later stages of the disease (Brown et al. 2000a,b). By contrast, there has been little research into the psycho-social impact of non-melanoma skin cancers (BCC and SCC), yet these also have the potential to be fatal if untreated. Whilst the prognosis may be better than that of MM, patients with a non-melanoma diagnosis must face treatments which may involve scarring or disfigurement as the result of the removal of the lesion.

Coping strategies (i.e. hopeful and goal-orientated thinking) are thought to moderate levels of anxiety and depression and to facilitate adjustment to a potentially life-threatening disease (Cassileth et al. 1982). Baider et al. (1999) and Holland et al. (1999) found that religious beliefs were helpful in coping with the threats imposed by MM by providing a way of putting the experience into perspective.

Much attention in recent years has focused on the work of Lazarus and Folkman (1984), who developed the concepts of emotion-focused and problem-focused coping, based on the premise that coping is dependent on the situation that is to be faced. Much of the research into coping has used self-report checklists. However, despite this being an established method for measuring coping, critics have argued that coping is then reduced to a score, and crucial elements such as timing and appropriateness may be lost (Carpenter 1992, Coyne & Racioppo 2000, Somerfield & McCrae 2000).

Little of the extensive research into coping with cancer has focused specifically on skin cancer. In addition, studies that have focused on MM are particularly scarce (Gibertini et al. 1992, Trask et al. 2001). Within the broader literature on coping with cancer, Somerfield and Curbow (1992) note the importance of appreciating the changing nature of coping strategies over the course of a stressful encounter. For example, different strategies may be employed at various stages in the disease process as patients are confronted with different treatment and illness-related stressors. Taylor’s (1983) work on cognitive adaptation to a threatening situation described the psychological factors involved in adjustment to chronic disease. This involved a search for ‘meaning’ (providing a causal analysis of why the event has occurred, restructuring one’s life in relation to perceived causal factors), ‘gaining a sense of mastery’ and the attempt to enhance self-esteem. However, little research has examined the psychological process of adjustment to a life-threatening illness (Brennan 2001). Brennan argued for adjustment to be regarded as a normal part of the adaptive process that may have both positive and negative consequences.

Skin cancer has often only been included in research that has examined a number of different types of cancer together (Harrison & Maguire 1995). Whilst this may be useful in terms of comparing the impact of cancer and identifying commonalities; it has provided little in terms of detailed analysis of the impact and consequences of the disease. Viewing cancer patients as a homogeneous group in this way ignores the unique diagnostic features of the different types of
cancer, yet these are extremely important in terms of subsequent treatment and psychological consequences (Kelly et al. 1999, Zabora et al. 2001).

Previous research in this area has mainly been carried out in Sweden, the UK, and Australia. Differences in public health policy in the UK, Canada and Australia have been examined and, whilst they are determined by different cultural, social and political influences, each of the countries sees that the individual plays a crucial role in the protection against skin cancer (Garvin & Eyles 2001). Reliance on quantitative research into both skin cancer and coping has meant that studies have been guided by researchers rather than patients, and so have failed to provide a clear understanding of the experience from patients’ perspectives.

The study

Aim

This study aimed to explore patients’ early experiences of skin cancer, including how they cope with the diagnosis, and to give suggestions for improved care provision.

Participants

Participants were recruited from a dermatology centre in the UK. A specialist registrar wrote to a total of 58 patients, who were at different stages in the disease trajectory to invite them to participate in the study. Twenty patients responded to the letters, including two relatives of patients who wrote to say that the patient had dementia and so would not able to take part in an interview. In addition, two participants were subsequently unable to attend an interview due to other commitments. People who returned the reply slip attached to the letter were telephoned to arrange an interview.

Sixteen interviews took place with eight women and eight men, who were aged between 24 and 90 years (mean age of 63.8 years). All participants were capable of responding verbally to questions and participants were selected without regard to ethnic origin or sex. Seven participants had received a diagnosis of BCC, four had SCC and five had MM. At date of interview, the time since diagnosis ranged from 3 to 48 months (mean of 8 months and 1 week).

Data collection

The interviews were conducted in a consulting room at the dermatology centre. They were discontinued when the interviewer judged that no new information was being gathered. The proportion of patients with the different diagnoses reflected the make-up of the clinic population, and thus more patients with BCC participated than with SCC and MM.

Interviews lasted between 15 and 45 minutes (mean of 35 minutes). All interviews were semi-structured, tape-recorded and transcribed verbatim. The interview schedule was based on the idea of mapping the person’s personal journey from initially discovering the skin lesion, through to referral and subsequent treatment. The following questions were asked:

- Could you tell me about your skin condition?
- What happened when you visited the clinic?
- Were you concerned about the treatment?
- What treatment did you receive? Did you have long to wait for the results?
- Do you have any ideas about what might have caused it?
- What do you know about the effects of the sun?
- In what ways has it affected your life?
- Has it changed your behaviour, i.e. in the sun?
- Have you got a scar and does this affect your behaviour?
- Is there anything that you have done or thought that has helped you to manage with it all?
- How do you feel about the care that you received?
- Is there anything that we have not covered that you would like to add?

Ethical considerations

Ethics approval for the study was obtained from the United Bristol Healthcare Trust. Patients were given an information sheet about the study prior to the interview. Care was taken not to mention the word ‘cancer’ on any of the written correspondence, and the word was not directly used by the interviewer at any point during interviews, unless participants chose to use such vocabulary themselves. This was to minimize any possible distress to interviewees that this might cause; but also so as not to influence the answers provided by participants, but rather to listen to their own interpretation of their diagnosis. Participants were informed that the interviews were confidential and any information provided would subsequently be anonymised. They were also told that the information gathered would be stored securely and destroyed after the study had finished. Information about a local Cancer Centre, which provides psychological and informational support, was offered to participants if the interviewer judged that they might benefit from such help. The names used below are pseudonyms.

Data analysis

Thematic content analysis was used to analyse the data. The first interview transcript was read through several times to get
a feel for any striking or interesting issues that emerged from the data. Preliminary comments were then made in the margin at the side of the text. The other side of the margin was used to note themes that began to emerge from the data.

The themes were entered into word processing software to form a list. Data that seemed to be connected, or helped make sense of other data, were grouped into cluster themes. Each interview text was continually checked to ensure that the themes accurately reflected what the participant had said. The final stage was to produce a table which defined the cluster themes under a main heading. At this stage certain themes were excluded if they were not well represented in the text or did not fit into the cluster themes. Thus, a heading was chosen and underneath this the relevant cluster themes were noted, with a reference as to where they had appeared in the text. This process was repeated for each of the interview transcripts. Although the first transcript was not used as a marker for the analysis of the other interviews, as the process continued the analysis of each subsequent transcript may have been primed by the themes that had emerged in previous ones.

Themes were then established across the data and the master themes were combined into one list. Although there were clear themes emerging from the transcripts that applied to a majority of the participants, it was decided to divide the master themes into the three diagnostic categories, to identify themes relevant to the participants of the three diagnostic groups.

The supervisor to the project analysed one of the transcripts and compared and discussed the similarities and differences between the themes that the researcher had identified, and a high degree of consensus was found.

Findings

Patients with carcinoma

Patients with BCC and SCC appeared to experience similar journeys through the process of diagnosis and treatment. Therefore, the themes that emerged from these two groups are presented together.

Reaction to diagnosis

The reactions of patients with BCC or SCC to the diagnosis were influenced by previous knowledge of skin cancer and the information given at the time of the diagnosis. When clear information was provided, patients felt little cause for concern. Conversely, they expressed anxiety when the diagnosis was not clearly explained:

…the consultant just had a look at it and said, ‘I think it’s a…’ and I couldn’t even remember the term after I got out of the hospital, but he said, ‘I think it’s a basal cell carcinoma’. Now the only thing I know about the word carcinoma is that it’s linked to cancer. And having shortly before lost my brother to cancer, I must admit I did initially go into a bit of a flat spin (panic)...When I realised afterwards exactly the nature of it and it was explained to me more fully, then obviously I calmed down. (Mary, BCC)

Language used to describe the diagnosis was also important. Patients picked up on significant key words such as ‘cancer’, ‘malignant’ and ‘benign’, and then made a judgement and subsequently expressed a reaction to the diagnosis, based on their interpretation of these words. Peter (BCC) said, “I wasn’t concerned for the simple reason that the doctor said it wasn’t, err, for want of a better word, ‘terminal’”.

Patients who expressed previous knowledge of skin cancer experienced a calmer reaction to the diagnosis, whilst those without such knowledge reported concern and a greater need for information, and were more sensitive about words such as ‘cancer’.

Satisfaction with care-causal attributions

BCC and SCC patients reported that they were satisfied with the care that they had received. The speed of the treatment, as well as the care by the hospital staff, played a crucial role in minimizing the experience and enabling participants to put it behind them:

I’m not normally one to take things lightly, but it…seemed to me to be categorised and it was dealt with, and that was that as far as I was concerned. (Penny, BCC)

Making sense of the disease

Although participants offered a number of reasons why they thought the cancer had developed, including over-exposure to sun, hereditary links, skin colour and living abroad, they all felt unsure of the cause:

…as I say, certain members of my family used to have various bits and pieces like that and so I wondered if to some extent these things were hereditary. (John, BCC)

None expressed any feelings of guilt or self-blame, and their causal attributions determined their behaviour, including self-diagnosis and attempts at self-treatment:

…it started as like a pimple…and I thought I’d been bitten, so I was putting (antiseptic) on it, trying to get rid of it. I was probably feeding it, if the truth was known. (Julie, SCC)

Not only did these participants display a lack of recognition of the signs of a cancerous lesion, but they also attempted to
Adaptation to the disease – minimizing the experience
Participants reported that the experience of being diagnosed with and treated for BCC or SCC had a minimal impact on their lives. This process was expressed in a number of different ways but typically involved comparisons that minimized the experience. Some patients put it in context in relation to other illnesses that they were more concerned about, such as diabetes, or focused on someone who had had a more serious illness, as James (SCC) illustrated when he said:

No, well, this diabetes that I got is more worrying, 'cos you don’t know what you can eat, what you can’t eat… I got the type two, with the tablet. It’s all right, but the foods so miserable – you gotta be so careful with what you eat.

Summary
Information and knowledge were key themes in the experience of these two diagnostic groups. The amount of information and the way in which it was assimilated was of key importance in how the diagnosis affected people. Patients had made sense of the disease by providing a causal attribution and, although a wide variety of possible causes was suggested, most felt unsure as to whether these actually were the underlying cause. All expressed satisfaction with the care that they had received, and this appeared to have played a crucial role in minimizing the impact of the experience.

Patients with malignant melanoma
Seeking medical help
There were a number of different routes which led these patients to seek medical help. In each of the three groups, participants did not seek medical help until others had persuaded them to do so, despite symptom changes. Of particular interest were the accounts by participants ultimately diagnosed as having MM who had tried to deny the possibility of anything being wrong, often by ignoring significant symptoms:

The trouble was I had had such a long period of just picking it and thinking it would go away I continued, and therefore my hankies were covered in blood and everything else. Just absolutely ridiculous. (Simon, MM)

Reaction to the diagnosis
All of the melanoma patients expressed some degree of shock at the diagnosis, and were more concerned by the diagnosis than were the previous two groups. The amount and type of information received at the time of diagnosis was influential for subsequent reactions:

‘…extremely upset, actually, and quite shocked, because I was told that it was very unlikely that it was anything…so I was shocked, to say the least. (Lorna, MM)

As with the non-malignant diagnostic groups, these participants were relatively calm when given the diagnosis if they had a clear understanding of MM and were reassured by the diagnosing clinician, as June (MM) explained:

Um…obviously when they told me it was cancer, the big ‘C’ word, it was scary…but I was still quite calm, because I was told that it was 0.6 mm. And if it’s over 1 mm, that’s when it’s got the potential to spread. So I was still quite calm and I thought, ‘Oh well, you know, we’ve caught it early enough, I’m not too worried.’

Coping – information seeking/religious faith
Participants with MM reported using a number of strategies to cope with the demands presented by their diagnosis. These included social support, social comparison, religious faith and avoidance of information. For example, one person described how his previous experiences with chronic fatigue syndrome had meant that he avoided reading a wide range of literature on the subject because of controversy surrounding the illness and a lack of causal basis or available treatment. This participant decided to adopt the same approach when diagnosed with melanoma:

I know some people like to read numerous volumes on their condition. I’ve never been one to do that…I’ve just gone on and, er, gone through it. (Simon, MM)

Participants reported using a number of coping strategies, including reliance on religious faith:

I have to say that I’m a Christian and I believe in healing, and so the whole thing wasn’t too much of a problem. I won’t say I wasn’t concerned, but the faith kept me going and I knew that other people were praying for me. (Simon, MM)

This man was able to draw on his faith for support, but it also provided a source of social support so that practical issues, such as taking time off work, were not a problem.

Making sense of the disease – social comparison/causal attribution
Two participants clearly described their illness in comparison with others in a similar situation in an attempt to rationalize their experience. One stated:
Issues and innovations in nursing practice

What it did do, I think, more than anything else, was to make me understand the effects, of the impact it would have on other people in more serious cases. (Adam, MM)

Comparison with others enabled enhancement of participants’ self-esteem, as they realised that they could be in a worse situation. This enabled the experience to be placed in perspective, in light of being told they had a serious and potentially life-threatening condition. A common theme amongst this group was that of minimizing the experience. For example, Lorna said; ‘I just thought, you know, it is one of those things, that it’s been noticed and it’s being treated’. This comment was made despite the fact that the participant had previously expressed being ‘extremely upset and quite shocked’ when she had initially been given their diagnosis. It suggests that the information and treatment with which people are provided serves to alleviate initial fears surrounding the diagnosis.

Adaptation to the disease – changing behaviours

Some participants in the MM group described how they had changed their behaviour as a result of the skin cancer experience. For example, changing their behaviour in relation to the sun and avoiding a suntan. For some the experience had changed their outlook on life, by encouraging a reflective process and thinking about and taking care of others:

…and making sure that people were OK and, just in case there was any further occurrence…and so, yeah, it sort of drew me up in terms of my mental approach to life. (Adam, MM)

Treatment/satisfaction with care

As with the BCC and SCC groups, treatment involved the removal of the lesion, and for one participant this also involved a skin graft and overnight stay in hospital. Again, participants expressed satisfaction with the care they had received, including the speed of treatment (often received on the day of diagnosis):

I think I am a bit of a coward myself, and if I would have had to go home and waited I am not quite sure whether I would have made it back. So I am glad that it was done on the day. (Sophie, MM)

This rapid treatment minimized the amount of distress caused by the diagnosis, and participants who had to wait for treatment reported a greater reliance on coping strategies.

Summary

Interviews with MM patients identified a number of themes similar to those raised by the BCC and SCC groups, such as seeking medical help only after the prompting of others and using comparison as a coping strategy. In common with the other two groups, and they also described how they now minimized the experience, the experience had been dealt with and it was not seen as having long lasting effects on their lives. However, they utilized a wider variety of coping strategies in particular in the phase after diagnosis and before and during treatment. For many the experience appeared to have had a more profound affect upon their lives.

Discussion

No claim is made that the findings are representative of all skin cancer patients’ experiences, but they do highlight salient issues in an area where research has been lacking. It is important to note that participants had been diagnosed in the 2 months prior to interview; however, it became apparent that some had been in the health care system for a considerable amount of time, and had received a previous diagnosis of skin cancer. Therefore, in terms of researching the skin cancer experience, many of the interview data were retrospective accounts of these experiences and therefore might have accounted for the relatively low incidence of anxiety and depression. Entwistle et al. (2002) noted that such accounts may be difficult to assess because of reliance on memory, which can be filtered through subsequent experiences. It would have been preferable to interview individuals as they were going through the experience, but this was not considered ethically or logistically possible.

The issue of information and knowledge at the diagnostic stage was pertinent for participants, highlighting the need for clear and straightforward information at the time of diagnosis. This supports work that has examined lay understandings of cancer consultations (Chapman et al. 2003). The current findings suggest that providing clear and understandable information could relieve anxiety. Participants did not appear particularly anxious, possibly because they were not receiving treatment at the time of interview (Brandenberg et al. 1994).

Accounts of the coping strategies used by patients with MM distinguished this group from BCC and SCC patients, in terms of the impact it had on their lives. Whilst there is very little comparative data of how patients cope with MM, Somerfield and Curbow (1992) discussed the general nature of coping with cancer. They noted the central importance of looking at coping as a dynamic process and examining it in relation to specific contexts, such as the treatment stage. Coping in the present study involved minimizing the experience and sometimes denying the potential seriousness of the illness, as also revealed in the work of Brown et al. (2000a,b).

Participants reported efforts to identify apparently rational causal attributions for their diagnosis. Taylor (1983) suggested that people rely on causal relationships to make sense of
their diagnosis as a way of restructuring their lives. It also seemed important in terms of externalizing any feelings of guilt that participants in the present study may have been in some way responsible for developing the cancer.

The overall impact of the cancer on people’s lives may also be related to the meaning that is associated with the disease. Participants in the present study all expressed minimal overall disruption to their lives. With one exception (a woman who was about to start radiotherapy), those in all three diagnostic groups felt they had managed to put the experience behind them and continue their lives without lasting psychological consequences. With the exception of the aforementioned participant, they viewed their illness with optimism and as an obstacle that could be overcome. This positive attitude appeared to be influential in their behaviour, supporting the work of Fife (1994), and might have been due to the fact that they had relatively non-invasive forms of cancer; whilst they were all at risk from possible recurrence, none had been given a ‘terminal’ diagnosis. For most, treatment had ‘only’ involved removal of the lesion and they described a high degree of satisfaction with this, typically related to its speed and the care given by staff. Similar findings of high levels of confidence were reported by Federman et al. (2001) in relation to primary care providers’ ability to diagnose, investigate and treat skin cancer.

This study involved interviews with patients given a diagnosis of malignant or non-malignant skin lesions. The two groups of non-malignant skin cancer patients experienced a similar journey and the experience seemed to have had a minimal effect upon their lives. Although patients with MM experienced a number of similarities to these two groups, they expressed a greater need for coping strategies, and reflected more upon the experience. It may be that the themes for these three groups of patients were similar due to the course of treatment that they received. For example, once in the hospital system, they all underwent a similar journey, which included a series of outpatient appointments and rapid treatment, which they said was of a high standard and enabled them to minimize the experience. Patients with MM might have reflected more and used more coping strategies than the other two groups, because the prognosis of MM is potentially more serious. Media coverage of skin cancer focuses predominantly on MM, and this may have contributed to making these patients more sensitized to the prognosis and implications of such a diagnosis. However, this group did not appear highly anxious, which concurs with other studies that have focused on MM (Brandenburg et al. 1992, Kelly et al. 1995). In addition, some of the more general work on adjustment to and experience of having cancer was also confirmed, such as the fact that participants made use of causal relationships to make sense of their cancer (Taylor 1983).

Conclusion

Outpatient clinics are capable of providing quick and effective treatment for skin cancers that allow patients to assimilate the experience, whilst leaving little lasting psychological damage. Patients with skin cancer, however, are not homogeneous, but rather are people who have diverse diagnoses and prognoses, consequences and experiences. Malignant melanoma patients may require additional support to deal with the consequences of the disease. Information provided in consultations needs to be given in a clear and straightforward manner, so that patients understand their diagnosis. There is an important role for nurses in ensuring that they understand this information, how to monitor their future progress and are enabled to use appropriate coping strategies to deal with their condition.

Acknowledgements

The authors would like to thank Dr M. Kirkup, Specialist Registrar, and the staff and patients at the Bristol Dermatology Centre.
References


Brown J.E., King P.N., Butow S.M. & Coates A.S. (2000a) Patterns over time in quality of life, coping and psychological adjustment in late stage melanoma patients: An application of multi level models. Quality of Life Research 9, 75–85.


