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ABSTRACT

Aims and objectives: To explore the patients' experience of having malignant melanoma, their related support needs and the processes that lead to these needs being met.

Background: The number of patients attending surveillance clinics after a diagnosis of malignant melanoma is increasing. In the UK specialist nurses provide support to patients but little evidence exists about the nature of patients' support needs or their experience of having melanoma. Melanoma has often been researched within general cancer studies, yet the support needs of melanoma patients may be different from those of patients with other skin cancers or tumour types.

Design: A Grounded Theory Approach was used to guide sampling, data collection and analysis.

Methods: In-depth interviews were conducted with eleven patients who were purposively sampled. Transcripts were read several times, coded and categorised using the constant comparative method. Emergent categories were discussed with participants.

Results: Three emergent categories related to a core category of melanoma-related worry which formed a substantive theory about the strategies patients use to control this. Participants reported needing to have their concerns believed by others prior to and after diagnosis. They discussed discerning whom to share their concerns with depending upon who they felt would not perceive assisting them as being burdensome. They also sought ways to reassure themselves.

Conclusions: Patients need to have their fear and worries acknowledged by others. This includes nurses, healthcare professionals and family members. Patients will also use self-examination and the absence of symptoms to reassure themselves.

Relevance to clinical practice: Nurses play key roles throughout the patient's care; therefore they need to be sensitive to the fact that patients may consider them a primary source of support. When teaching self-examination it is important that nurses discuss that this may ease worry and aid coping.

Keywords: Melanoma, Supportive Care, Clinical Nurse Specialist

SUMMARY BOX

Patients see melanoma as being different to other cancers, which may result in feelings of isolation.

Patients with melanoma make deliberate choices about sources of support and nurses need to be able to recognise when they have been chosen for this role, so that they may provide adequate support.

Self-examination, while a method of surveillance, is also used as a means of reassurance that melanoma has not recurred. This should be considered when teaching

self-examination to patients.

INTRODUCTION

Melanoma is a cancer of pigmented cells and the most aggressive skin cancer. Incidence has increased in recent years but the number of deaths has remained relatively stable (CRUK 2012). This trend has been observed in the UK, Australia and parts of the US, which may be due to early diagnosis resulting in curative excision (Bataille & Vries 2008). The standard care for patients who are disease free following surgery is considered to be regular surveillance (Marsden et al 2010). Some patients experience disease recurrence, undergo multiple surgeries and attend clinics for many years. This increasing number of patients is placing greater demands on existing services.

Within the United Kingdom, recommendations have been made that each multi-disciplinary team should include a Skin Cancer Clinical Nurse Specialist (CNS) whose role is to support patients and carers, ensure equality of access to information, identify and respond to the needs of patients undergoing disfiguring treatment including psychological support (NICE 2006a). When developing guidance for the care of people with skin tumours including melanoma, the National Institute for Health and Care Excellence (NICE 2006a) found a lack of evidence regarding the experience and needs of this patient group. This left nurses with the challenge of providing services to meet the needs of melanoma patients with limited evidence on which to base care. For nurses to provide evidence based care, it is important that there is an understanding about the experience and unique needs of patients with melanoma. Where nurses are aware of identified needs relating to specific patients groups, care, information provision and support can be tailored to the needs of the individual.

BACKGROUND

A search for literature published after the NICE Guidance (2006a) demonstrated an increase in research activity regarding the needs of melanoma patients, but the majority of the evidence is generated from self-administrated questionnaires measuring health related quality of life (Cornish et al 2009, Cashin et al 2008) rather than exploring the processes experienced by patients. General questionnaires might not be sensitive enough for patients with early stage melanoma as they do not contain melanoma specific items, such as sun avoidance and economic issues, that have been shown to have an impact on this patient group (Holterhues et al 2011). Only studies that considered melanoma patients as a discrete group following diagnosis were considered as their needs may differ from other cancer patients. Patients experience anxiety, distress and sometimes somatic symptoms while

waiting for a diagnosis of melanoma, but also a sense of relief on completion of treatment or check-ups (Burdon-Jones et al 2010, Cornish et al 2009, Smith 2012,).

A small study found pre-surgery melanoma patients use less effective coping strategies than patients requiring surgery for benign skin conditions (Trapp et al 2012). When looking at the adjustment of melanoma survivors, cognitive appraisal was found to make a greater difference to the adjustment of melanoma survivors than disease related variables such as cancer stage at diagnosis or time since diagnosis (Hamama-Raz et al 2007). Those who were more likely to experience negative emotion and less likely to express emotion socially were found to have poorer health status than those with other personality types (Mols et al 2010). Psychosocial factors may therefore be as important in determining patient outcomes as the pathological features of the disease and nurses may be best placed to assess these.

Patients with a diagnosis of melanoma have specific information, emotional and psychosocial needs, but ways to address these needs are not identified. In studies examining the needs of all cancer patients non-melanoma skin cancer as well as melanoma, differences were found between the subgroups based on types of cancer (Al-Shakhli et al 2006, Burdon-Jones 2010), which indicates patient needs may differ based on the type of cancer they have. This suggests that patients with melanoma may have specific needs, but these specific needs are unknown.

Findings from several studies suggest that melanoma patients require comprehensive and relevant information that relates to their situation (Constanidou et al 2009, Al-Shakhli et al 2006, Hertz & Tomasone 2012, Passalacqua et al 2012). These needs are not always met (Kasparian 2013). Self-examination of skin and lymph nodes among melanoma survivors is not always complete and frequency can vary considerably (Bowen et al 2012, Mujumdar et al 2009). The use of support services from psychologists, social workers, oncology nurses, physiotherapists, other patients and spiritual care were found to be sporadic (Mols et al 2010).

It was unclear whether patients require a more comprehensive service, or whether existing services are adequate. Although the support needs of patients with melanoma may be met by clinical nurse specialists, oncology nurses, community nurses and voluntary services, there is a lack of clarity about the type of needs melanoma patients have and what type of care is helpful. CNSs have been linked to improved patient outcomes (Department of Health 2012) but the mechanisms of these improved outcomes are not clear. Exploration of the experience and support needs of patients with melanoma, considering the social process involved in their care is therefore required to understand current provision further.

STUDY AIM

To explore the patients' experience of having malignant melanoma, their related support needs and the processes that lead to these needs being met.

METHODS

Design

To examine the social processes within service provision that make up patient experiences and support mechanisms, an inductive approach was considered beneficial, allowing participants to freely express their personal experience and identify what was important to them. A Grounded Theory approach was therefore chosen as it lends itself to the examination of social processes. The original Grounded Theory Methodology described by Glazer & Strauss (1967) has been criticised for being objective and could be considered at odds with the partnership working currently considered within the National Health Service. A constructivist approach to the method suggested by Charmaz (2006) was therefore used to allow the participants to guide the study, while using a structured analytic process. Themes identified from the literature review were used to guide the study, but these were not imposed upon it and those found to be irrelevant were dispensed with (Charmaz 2006).

Participants

Eleven participants were recruited via melanoma clinics at a specialist cancer centre in England seeing approximately 140 new melanoma patients each year. Inclusion and exclusion criteria are shown in Table 1. Patients were approached following their routine hospital out patient appointment by a member of the medical team and if the patient wished, the researcher discussed the study with them. Patients then had the option to make an appointment for the interview if they were keen to take part, or to receive a telephone call from the researcher a few days later to answer any further questions or arrange the interview.

Sampling Procedure

A theoretical sampling procedure was employed in order to seek pertinent data to develop emerging categories and theory (Charmaz 2006). The first three participants were identified from all eligible participants attending clinics in the first weeks of recruitment. The data collected from these three participants demonstrated some similar experiences and needs which warranted further exploration and indicated that the next participants should have experienced some recurrent disease. It was anticipated that the length of time since the original diagnosis could have an effect on the data so this was taken in to account during

subsequent sampling. The emerging categories needed to be tested through the constant comparison of new data that may challenge it. The final participants were selected to test whether stage in the life cycle influenced the emerging categories. As the new data did not conflict with earlier data, or suggest that new factors should be explored, data collection ceased when 11 interviews completed and emerging categories appeared to be saturated. Demographic details of the 11 participants are shown in Table 2.

Data collection

Data collection took the format of in-depth interviews. These were audio recorded for accuracy and to enable the researcher to focus on the participant. Interviews were carried out face-to-face at the participants' choice of setting: their home or the research centre. Initial topics to be addressed in the interviews were identified from the literature but this then evolved to explore emerging categories.

Questions were phrased to include initial open-ended, intermediate and ending questions (Charmaz 2003). Example questions were discussed and tested with a patient representative prior to the first interview to ensure issues pertinent to the patients were included. The style of questioning was also discussed and how patients could be supported if any on-going issues were raised from the interview. Interviews were performed in a conversational style with probes being used to encourage the interviewee to share information (DiCicco-Bloom & Crabtree 2006). Topics and questions evolved as the interviews progressed to reflect the emerging categories. Questions about lifestyle changes were added to included self-examination and additional questions about melanoma worry were incorporated.

Analysis

Audio recordings were transcribed and anonymised to maintain confidentiality. Transcripts were read several times to gain familiarity with the data. Constant comparative methods were used throughout the analytic process with data collection and analysis taking place concurrently (Glazer & Strauss 1967). Initial coding was performed line by line to form emergent categories from the transcripts. Initial, axial and theoretical coding were then used synchronously to link categories and determine their properties (Charmaz 2006). NVivo 8 was used to assist analysis.

Rigour

Rigour was addressed by attending to Lincoln & Guba's criteria for trustworthiness: credibility, transferability, dependability, confirmability (Lincoln & Guba 1985) and authenticity (Guba & Lincoln 1994). As a member of the wider clinical team the researcher

had experience of the field but was not directly involved in the care of patients recruited to the study. A reflective diary was kept in order to record why particular decisions were made, aid interpretation and ensure transparency of the process. Reflecting back on analytic decisions enabled the researchers to ensure that data was grounded in patient responses rather than researcher generated. Emergent categories from initial interviews were discussed with later participants to check meaning and relevance. Interviews were transcribed by listening to the recordings several times and correcting errors in transcription. During analysis recordings were listened to while reading the transcripts to maintain the original meaning of participants. Analysis was conducted by JB but emergent categories and selections of the transcripts were also discussed with SD and PC to ensure accuracy of the interpretation. As JB & SD worked in the wider clinical area, PC was able to provide a differing perspective on the data.

Ethical Considerations

The research was approved by the regional ethics committee. The principles of the Research Governance Framework for Health and Social Care (DH 2005 & 2008) were followed and necessary approvals gained. All patients were given a copy of the Participant Information Sheet to take home. Written informed consent was obtained prior to interview. This took place at least 24 hours after patients were approached in line with good ethical practice. Participants were assured that their participation would remain confidential and would not affect their care.

RESULTS

Three conceptual categories emerged to explain how patients deal with and control melanoma-related worry, which formed the core category. This led to a substantive theory about strategies to control melanoma-related worry. Patients discussed a need for their concerns to be believed (being believed and allowed to worry), how choosing someone to share the burden of worry with eased this (sharing the burden) and the strategies they employed themselves to reduce their worry and enable them to carry on daily life (doing something to help yourself). The categories and their properties are presented below and in Table 3.

Melanoma-related worry

At the time of diagnosis participants spoke about feeling '*frightened*', '*scared*', '*fearful*', not being '*brave*', being '*overwhelmed*' or feelings of '*trepidation*'. Regardless of whether patients experienced recurrence the thought that the melanoma could come back remained. In dealing with uncertainty participants contemplated the consequences of recurrence or death. They talked about hope and making the most of the time they had as they considered

their future and mortality. They looked for reassurance that treatment would be available if needed and started to put their affairs in order in case they couldn't at a later date.

The anxiety caused by the melanoma diagnosis has a greater magnitude at the beginning of treatment and participants talked about worry lessening with time. Participants talked about their confidence that the disease was not going to return increasing with time. As such one patient stated that self-examination had lessened over time as their confidence had grown. When thinking about the possibility of being discharged from the hospital, patients expressed a wish to reduce the number of visits, but did not want them to stop.

Being believed and allowed to worry

Throughout the pathway patients needed to be believed by others including healthcare professionals, relatives and friends. They also considered the public perception of what it meant to have melanoma. In particular they needed to have their fears or concerns believed and understood to be real.

All patients initially sought advice from their General Practitioner (GP) about something that was not normal and may have caused them to worry. Where symptoms were not deemed problematic, participants stated that they were reassured but this did not make the participant feel as though their concerns were warranted or believed. Reassurance was not lasting as they sought help again, presenting several times until treatment was offered. Patients were persistent in seeking someone (other GPs or nurses) to believe their concerns and validate the worry they experienced. The worry related to the presence of symptoms was not relieved until they were absent and regular reassurance was not enough.

The need to have someone believe that their concerns were real and justified continued throughout the patient experience. The terms melanoma and cancer or skin cancer were used almost interchangeably in the interviews, but seen as being different to other cancers. The relative rarity compared to other cancers was a part of this. Patients felt that melanoma was not seen as being as serious as other cancers so other cancer patients, family and friends did not acknowledge their fears. Having their diagnosis played down or not taken seriously by other patients, friends or relatives made participants' concerns seem unwarranted. The self-perception of not being physically incapacitated contributed to melanoma being less serious. The more serious melanoma was perceived to be by participants, the greater the concern expressed. Sharing it with family, friends, or healthcare professionals relieved this worry or concern.

Sharing the burden

Emotional support was described as having people to talk to and involved family, friends, nurses or other health care professionals (HCPs). Talking about it lessened the worry associated with a melanoma diagnosis. Being able to talk about feelings was seen as a release, a way of dealing with them. When deciding whom to talk to participants chose the person that they felt could cope best with the burden of their problems. Participants talked about the times where they felt alone as being difficult.

The main source of support for most participants was their partner. Two talked about the reciprocal element of support where their partners had also experienced illness, which they felt strengthened their relationship. Other participants, however, chose not to talk to family in case it added to their burden. This was also the case where participants had adult children who they didn't want to burden with their problems. Friends also provided this role either in addition to family, or where family support wasn't either available or appropriate. This was particularly the case when wanting to discuss death and partners weren't ready to talk about the related issues.

Where family and friends were not available or chosen as a source of support, then HCPs were used. This was most often the CNS as they could be contacted easily. The need for this support continued long after diagnosis and treatment and participants felt able to talk to nurses in terms that they understood.

Participants remarked on the importance of being treated as an individual and building a relationship with the CNS so that treatment and information could be tailored to their needs. The drawback to this familiarity can be a level of dependence. One participant revealed how changes in staff after a number of years were difficult to deal with. Where the CNS was not selected, it was because the participant felt that they could not take the burden.

The majority of patients had not spoken to other melanoma patients for support. Only one participant had spoken to another patient prior to their treatment and found this a positive experience as it enabled the burden to be shared with someone who truly understood and believed their concerns. One other participant had acted as a source of support for someone else diagnosed with melanoma after his own. The participant found that in counselling someone else, he also felt better about his own situation, relieving his own worry.

While the main reason for not talking to other patients was found to be not having the opportunity to meet them, participants were wary of talking to people who had more disease and feeling worse about their own situation. In talking to other patients, there would be the

risk of taking on some of the burden of someone else's situation or feeling guilty about putting their concerns on to someone that did not have the capacity to take them on.

Two of the participants accessed complementary therapies for counselling and relaxation. The main benefit voiced was that they could access someone independent from the hospital and without feeling that they were burdening a family member. It is worth noting, however, that both participants that accessed complementary therapies were treated some time ago, prior to CNS roles and during the interviews they both mused on whether this additional support would have changed anything for them.

Doing something to help yourself

Throughout the patient journey, a need to actively do something to prevent recurrence was noted and this offset some worry associated with melanoma. Multiple surgeries including skin grafts may be needed. This gave patients a sense that they were doing something about it. After surgery though, there was a realisation that this was not the end and that treatment, at least in the form of surveillance, would be needed. During follow-up, some participants expressed a need to do more to help themselves. Two participants had accessed counselling and relaxation services and one had modified their diet. Others expressed a need for information on lifestyle changes that could prevent recurrence, but had not found any. The lifestyle change common to all patients was that of sun avoidance. All participants discussed this in some way, reflecting on past behaviour and additional measures now taken to prevent further melanoma. This also extended to their families, as they wanted to ensure that family members were also protected from sun exposure.

Reference points were found in order to enable participants to put the melanoma diagnosis in to context for themselves. This firstly involved weighing up previous experiences or understandings of cancer. Other healthcare priorities, often as experienced by the patient or a close family member also aided to construct the patient's perspective of how melanoma affected them. For one patient a pre-existing condition sometimes took precedent over cancer treatment. Two of the participants in the study were pregnant during their diagnosis so the safe delivery of their baby was the main concern.

Where another illness affecting a close family member contributed to the construct of the patient's meaning of melanoma, this was often used to judge the severity of the effect of the melanoma. Some patients used previous family events to give context to how difficult they were finding the situation. To give the sense that they had been through what they perceived to be worse experiences before. These reference points are then used in questioning and bargaining processes as the individual makes sense of the diagnosis and how it affects

them. While weighing up the gravity of the situation patients considered how bad their melanoma was and made comparisons to situations that they considered worse.

Patients who receive a diagnosis of melanoma experience significant worry. While they try to manage this anxiety in many ways, it impacts many aspects of their daily life. Noting the absence of symptoms and self-examination were used for this with male participants practicing self-examination most often. Where the participant had more confidence in HCPs rather than their own self-examination, they found the follow-up essential, especially where they had required more than one treatment. Compliance with follow up visits was also viewed as a way to help themselves. These caused anxiety beforehand but reassurance afterwards for the majority of participants, which gave them permission to not think about melanoma until their next hospital visit.

DISCUSSION

Patients who receive a diagnosis of melanoma experience significant worry which is managed in ways that affect many aspects of their daily life. The anxiety caused by potential new or recurrent disease persists for years after diagnosis and relates to knowledge that metastatic disease is not curable (Mcloone et al 2012). This worry is dealt with by sharing it with whomever is felt to be the most appropriate person and engaging in activities to prevent recurrence of the disease or give context to their diagnosis.

Where participants had needs that were not met by existing services, they found a way to fulfil these needs themselves. This included: finding information, finding an independent person to talk to, finding another HCP to talk to and making lifestyle changes. This independence should be maintained, but where participants in this study were proactive in meeting their own needs, not all patients may be able to do this leaving them with unmet needs.

The perception that melanoma is different to other cancers supports the suggestions of NICE (2006a), Al-Shakhli et al (2006) and Burdon-Jones et al (2010) that the needs of melanoma patients may differ to those with other types of cancer. The findings from this study show that preconceptions of melanoma and its severity can affect the patient's experience. This may relate to a lack of public understanding. The feelings of isolation and needing to be believed should to be recognised by nurses and other HCP so that they do not inadvertently play down a patients concerns, and instead ensure that they are addressed. The view of melanoma not being a serious cancer may be related to disease stage and experiences may be different if patients with metastatic melanoma had been interviewed. Findings from another study of twenty melanoma survivors found that participants compared

their experience to those of people with other cancers and did not consider melanoma to be as concerning as treatment had not included chemotherapy (Mcloone et al 2012).

The findings of this study suggest that melanoma patients seek support from a variety of sources but choose the one most appropriate to them. This is often their partner. Participants most likely to use complementary therapies or CNS for support were those who did not have partners or didn't want to burden them with their anxieties. Identifying these patients to provide support may minimise the distress experienced. If patients see themselves as a burden to others then they may need to be given permission to access these services. Conversely, where patients are successfully supported by family and friends, and do not want additional services, it would not be appropriate to provide this. This research only explores the perspective of the patient, whereas their family or carers and nurses or other HCPs provide the support network which further work will explore. There is also a role for complementary therapies and peer support but the use of these support systems needs to be explored further.

The greater need for reassurance at the beginning of follow-up may warrant more flexible follow-up patterns. This finding mirrors that of Burgess et al (2005) who found increased levels of depression, anxiety, or both in the first year after a diagnosis of early breast cancer highlighting the need for dedicated service provision during this time. It could be that additional support visits for melanoma patients could be provided by the CNS either in clinics or via telephone. It is also appropriate for surveillance visits to be performed by the CNS. Patients in our study were able to form a therapeutic relationship with the CNS more than other HCPs, which gave them a sense of individualised care. This may contribute to CNS involvement being linked to improved patient outcomes (Griffiths et al 2013). Multidisciplinary follow up clinics provide a flexible service for this diverse patient group.

Findings relating to the use of self-examination as a method of reassurance differed to those found by the report commissioned by NICE (2006b). NICE (2006b) found that patients were worried about missing things and only twenty per cent were happy to self-check. In this study, however, self-examination was found to be used as a coping mechanism, particularly by male participants. Following completion of the research, one other study conducted in Australia also found self-examination to be used to provide reassurance that no new disease was present (Mcloone et al 2012), suggesting that this finding may be applicable to wider clinical settings. Another study of 48 melanoma survivors, however, found that self-examination of skin and lymph nodes was not always complete and frequency varied (Oliveria et al 2013).

While used as a coping mechanism for some participants, self-examination is important for the detection of recurrent disease. Brecht Francken et al (2007) found that three-quarters of first recurrent melanomas were detected by patients or their partners. The authors therefore suggest that improved patient education could reduce the frequency of follow up while being safe and economical. Evaluation of the effectiveness of educational packages would be needed, especially in later years, as one participant spoke of performing less self-examination as time went on. This would also need to be tempered with some patients not having partners to check areas that were difficult to see and the reassurance gained from regular surveillance.

Providing evidence based information on ways that patients may do something to help themselves may also be beneficial. General lifestyle advice regarding diet, exercise and sun protection for the future may be helpful. Melanoma survivors become more aware of the need for sun protection, which can cause them to change their lifestyle to limit exposure (Oliveria et al 2013, Mcloone et al 2012).

Limitations

Participants were aware of the study aims prior to interview but the open questioning and inductive approach aimed to reduce the possibility of participants saying what they thought the researcher wanted to hear. All participants were volunteers and may have had particular issues that they wanted to be known that could differ from non-participating patients. There may therefore be additional issues that could not be explored by this research method. The small homogeneous sample may not be representative of all melanoma patients.

CONCLUSION

The participants in this study viewed their needs as unique compared to people with other cancers. This resulted in them feeling isolated. The uncertainty of the future and possibility of disease recurrence can be very difficult to live with. Participants may feel that their anxieties are not warranted and need someone to believe them for their worries to be valid.

In order to cope with these feelings, patients choose individuals to share the burden. This may be a partner, family, friends, other patients, nurses or other HCPs. Nurses may be chosen as the main source of support as frequent contact with the patient allows them to build a relationship with the patient. It is therefore important for nurses to recognise when they have been selected for this role so that they can meet patients' needs. Sharing the burden of melanoma related worry lessens it for the patient.

Participants also expressed a desire to help themselves and wanted information on ways to prevent recurrence. Self-examination was often used by patients to reassure themselves that the melanoma had not recurred.

RELEVANCE TO CLINICAL PRACTICE

The feelings of isolation caused by a melanoma diagnosis may be related to a lack of public awareness of melanoma and how it differs from other types of cancer. This may be related to a general lack of awareness of melanoma and should be addressed on a population level. The amount of treatment required is not proportionate to the degree of worry experienced by patients. Nurses may be best placed to identify this anxiety as they come in to contact with patients in a variety of settings throughout the complex pathway of melanoma diagnosis and treatment: general practice, outpatients clinics, wards and community.

The patient will choose whomever they feel best able to talk to at that time whether this is a specialist nurse or someone independent of their cancer care. It is important that patient's worries and concerns are listened to and believed in all care settings and for nurses and HCPs to recognise their part in the patient's support network. They may be part of a large network or the main person chosen to share the burden of the patient's diagnosis. Holistic assessment should include discussion about the patient's support network. Identifying a need for support that is not met elsewhere may mean that nurses can allocate an appropriate amount of time to those patients or suggest additional sources. Peer support may reduce feelings of isolation.

This study adds weight to existing evidence that self-examination is used to relieve anxiety. Recognising that patients use self-examination as a method of reassurance should be considered when teaching this to patients and open discussion about this may aid patient counselling.

WORD COUNT 4941

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Table 1: Participant inclusion & exclusion criteria

Inclusion
Over 18 years of age
Able to understand what the study involves and give informed consent
Histological diagnosis of melanoma
No clinical evidence of metastatic disease in situ
May have had one or more surgical procedure for melanoma
Must be attending clinics for regular surveillance
Exclusion
Under 18 years of age
Not able to give informed consent
Recurrent or metastatic disease in situ at recruitment
Requiring treatment for melanoma at recruitment

Table 2: Participant demographics

Participant ID	Gender	Age	Time from diagnosis	Stage at diagnosis	Stage at recruitment	Number of surgeries	Other treatments
P01	F	61	1 year	IIC	IIC	3	
P02	F	31	1 year	IIB	IIB	3	
P03	F	68	1 year	IIIB	IIIB	2	
P04	M	77	4 years	IIC	IIC	2	
P05	M	42	8 years	IIC	IV	6	Radiotherapy
P06	M	63	5 years	II*	II*	2	
P07	M	67	1 year	IIIB	IIIB	5	
P08	F	71	11 years	IIIB	IV	7	Interleukin & Interferon
P09	F	83	5 years	IIC	IIIB	2	
P10	F	36	7 years	IIC	IIIB	3	
P11	M	70	3 years	IIC	IIIB	6	

* Further staging not available as removed by curettage.

Table 3: Emergent categories and their properties

Category	Property	Dimension	
Melanoma related worry	Feeling Isolated	Worry not being understood by family and friends	<p><i>"It was a bit frightening sort of being out there and of course everybody else in the hospital, you know with lumps in their breast, lumps in bowels and I'm sort of saying melanoma. And they all seemed to say oh is that all it was, you know, and yet mine was probably more dangerous...." Participant 08</i></p> <p><i>"...it was a bit isolating I think because it's not your usual cancer... It was hard. I just felt as if I were a bit out on a limb." Participant 09</i></p>
		Uncertainty of future recurrence	<p><i>"I would be worried if I wouldn't be checked regularly...even now, they discover. Well not every time a mole which started behaving badly." Participant 05</i></p> <p><i>"...then it meant the 40% chance of you know it spreading further.... But touch wood so far we're staying on the 60% side." Participant 10</i></p>
	Not knowing if it will come back	<p>Wondering if there will be treatment if it does come back</p> <p>Thinking about mortality</p>	
Being believed and allowed to worry	Not being believed	Repeatedly asking for help for persistent problem	<i>"So every six months I said while you're at it just have a look. And it was always looked at, no it's alright, no problem." Participant 11</i>
		Not being ill or sick	<i>"I've never been ill with it. Never had a day off work with it. So it's not, it hasn't been an illness in that respect." Participant 06</i>
		Melanoma is cancer	<i>"You're in a lot of trouble, you've got cancer ... It's like a death sentence isn't</i>

		It is serious	<i>it until you actually get things sorted out.” Participant 09</i>
Doing something to help yourself	Getting rid of it	Having surgery	<i>“Every surgery on its own is painful, obviously at the beginning. But the idea of, you know, that every surgery is making you better. That helps a lot.” Participant 05</i>
		Having chemotherapy or radiotherapy	
		Trying alternative treatments	<i>“...when I was going through the treatment I looked in to some diets ... and I looked at an alternative treatment with cancer”. Participant 08</i>
	Monitoring	Attending follow up visits	<i>“...soon as everybody said you’re alright for the time being, that’s gone out of my mind then.” Participant 04.</i>
		Self-examination	<i>“I come to [the hospital] every 3 months, but they do no more than, than what I do every day.”</i>
		Compliance with follow up	<i>“ I check in the shower every morning” Participant 06</i>
Reducing anxiety	Other things are worse	<i>“My husband had major surgery and they’ve left him with a numb left leg and he gets a lot off pins and needles. But I didn’t think mine was as severe as his.” Participant 01</i>	
	The melanoma could be worse	<i>“Well there are so many people that are dying from melanoma that I consider myself very lucky.” “I think because we’ve been through it with my Mum, it’s like I say, we’ve been</i>	

	Sun avoidance	Avoiding sun exposure Using sun protection Perceived risk from sun exposure	<i>a little bit desensitised towards cancer and you just sort of take it as it comes.”</i> <i>Participant 02</i> <i>“I’ll put some factor 50 and 60 on you know Even winter like, you know if it’s a clear day having to put sun lotion on in November and things like that you know.”</i>
Sharing the burden of worry	Choosing to share the worry	Someone who has room for my problems Someone who knows me Someone separate from the hospital or family Strengthening relationships Exchanging experiences Gaining reassurance	<i>“I ask them anyway but sometimes you feel more comfortable asking somebody who you’ve seen on a regular basis like, you speak on a one to one. You get a bit more personal with them like don’t you. They know you, your lifestyle.”</i> <i>Participant 04</i> <i>“I spoke to one of my best friends. She’s Godmother to my children, I spoke to her about it. I suppose more when I didn’t want to worry my husband about things, she’s the other person that I could sound off to...”</i> Participant 10
	Choosing not to share the burden of worry	Not bothering people Not adding to the burden of family	<i>“You see how busy people are and that’s a put off. They’re rushing up and down and doing this and doing that. I think I don’t want to bother her.”</i> <i>Participant 07</i>

