

Title

The needs and experiences of skin cancer patients: a qualitative systematic review with meta-synthesis

A running head

Needs and experiences of skin cancer patients: a meta-synthesis

Word count 3,879

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What is already known about this topic? 70 words

Skin cancer is the most common cancer in humans.

Incidence of skin cancer is high compared to other malignancies and is increasing.

Few studies have directly investigated the psychosocial effects of keratinocyte carcinoma and its treatment

A previous review included only two studies that looked at the needs and experiences of skin cancer patients

What does the study add?

12 additional studies were identified.

These focused primarily on melanoma.

Diagnosis of any type of skin cancer can be distressing and its experience is dependent on its type and severity.

Patients need emotional support and information that should be tailored to the stage of their particular skin cancer journey

For all skin cancer patients, their experience continues post-treatment, with ongoing needs for information about risk management and skin cancer detection.

Summary (Abstract) 250 words

Background

Skin cancer incidence is increasing worldwide. This is an update of a previous review published in 2010 that identified only two studies and found that the needs and experiences of individuals with skin cancer were under-researched.

Objectives

To undertake a qualitative systematic review of the needs and experiences of people with a diagnosis of skin cancer.

Methods

As an update of a previous review, the following databases were searched from 2010 to 30/11/15: CINAHL PsycINFO, MEDLINE and EMBASE. The methodological quality of the studies was assessed using the Joanna Briggs Institute (JBI) Qualitative Assessment Review Instrument (QARI). The qualitative research findings were synthesised using a pragmatic meta-aggregative approach.

Results

Fourteen studies (16 papers) were included. Only three studies included keratinocyte carcinoma patients. 15 categories were identified and these resulted in four overarching synthesised findings (SFs) from diagnosis (SF1) through treatment (SF2) and follow up (SF3), and then a fourth SF (SF4) that addressed patients' satisfaction with their care and their relationship with health professionals.

Conclusions

Despite the fact that keratinocyte carcinoma and melanoma patients can have very different prognosis, they also share similar needs and concerns especially around the time of diagnosis and follow up/surveillance for new lesions. Health professionals working with skin cancer patients need to understand their psychosocial concerns, and their information needs in order to design services appropriately. Future studies need to consider keratinocyte carcinoma patients as well as melanoma patients.

Introduction

Skin cancer is the most common cancer in humans and the incidence is increasing worldwide ¹. There are two main types of skin cancer: melanoma and keratinocyte carcinoma. Keratinocyte carcinoma makes up approximately 97% of skin cancers which are either basal cell carcinomas, or squamous cell carcinomas, together with some rarer types. Currently, between 2-3 million keratinocyte carcinomas and 132,000 melanoma skin cancers occur globally each year and one in every three cancers diagnosed is a skin cancer [WHO 2014]. Skin cancer affects people from all communities and age groups. Although keratinocyte carcinoma is mostly seen in the over 50's, increasingly it is being seen in younger people ^{2, 3, 4, 5}. The large increase in skin cancer incidence and the fact that keratinocyte carcinoma comes with high rates of recurrence and subsequent primaries ⁶ presents a significant challenge for all health care systems.

Patient needs and preferences comprise a core component of evidence-based medicine ⁷, yet, the support needs and experiences of skin cancer patients have received limited in-depth attention. This is despite a long standing recognition that additional research in this area is required (Improving outcomes for people with skin cancer tumours including melanoma, NICE 2006). Qualitative research is ideally suited to provide an in-depth picture of skin cancer patient needs and experiences, but, until fairly recently, most empirical research has been quantitative in nature ^{8, 9} and has focused primarily upon melanoma. In 2011, one of the authors of this paper [FBH] published a qualitative systematic review and found only two studies that had examined the needs and experiences of people with skin cancer ¹⁰. Qualitative systematic reviews have an important role to play in terms of informing healthcare professionals about the meaningfulness, feasibility and acceptability of healthcare interventions ¹¹. Recently there has been increased interest in conducting qualitative research in dermatology ¹² and, therefore, an update of the previous review is timely in order to inform practice and enhance the patient experience of having a skin cancer.

Material and Methods

This review adheres to the ENTREQ guidelines ¹³ and follows the Joanna Briggs Institute (JBI) methodology for qualitative systematic review ¹⁴. This is an update of a previous review¹⁰. The review considered adults with a diagnosis of either keratinocyte carcinoma or melanoma skin cancer in any setting. The phenomena of interest were the needs and experiences of adults following a diagnosis of skin cancer. All qualitative studies (including, but not limited to ethnography, phenomenology, and grounded theory studies) that met the inclusion criteria were considered. Qualitative elements of mixed method studies were also included if the qualitative data were presented separately within the publication. The search strategy was designed to be thorough and exhaustive and there was no restriction on language. All relevant studies were considered irrespective of date of publication. Relevant key words appropriate to the review objectives were identified following consultation with information specialists. The following databases were searched from 2010 to 30/11/15: CINAHL PsycINFO, MEDLINE and EMBASE. An example of the search strategy for Medline on Ovid is

given in Table 7. As per current methodological recommendations ¹⁵, this was designed to be sensitive rather than specific. The initial search results were exported to EndNote and duplicates removed automatically. Manual entry of studies identified from hand searching of reference lists of studies were entered into EndNote separately.

The titles and abstracts identified from the search were all independently assessed against the inclusion/exclusion criteria by two reviewers and there were no disagreements between the two reviewers. Full text papers were obtained of relevant studies and again assessed. There was only one paper which the two reviewers disagreed with and this was resolved by involving a third reviewer. Studies meeting the inclusion criteria were then independently assessed by two reviewers for methodological quality using the JBI Qualitative Assessment and Review Instrument (JBI-QARI) ¹⁶. There were no disagreements and therefore no need to involve a third reviewer.

Data extraction utilised a standardised JBI-QARI tool. Two reviewers read each paper several times to gain an overall understanding of the key findings and to set them in context. One reviewer then extracted the findings from included studies, variously reported as themes, metaphors or categories. Where possible, each extracted finding was supported by a verbatim quote from a research participant to illustrate its meaning. Where this was not possible, the author's narrative was extracted. All findings were assigned a level of credibility (unequivocal, credible and unsupported). Levels were assigned depending on the extent to which supporting quotes, detail and relevant context were available and lent weight to the finding's credibility, as per JBI guidelines [JBI handbook]:

- Unequivocal: Findings were accompanied by illustrations that were beyond reasonable doubt and therefore not open to challenge.
- Credible: Findings were accompanied by illustrations that lacked a clear association and were therefore open to challenge.
- Unsupported: Findings not supported by data.

Two reviewers independently reviewed the extracted findings and the assigned levels of credibility and reached agreement that they were appropriate for each paper. There were no disagreements regarding level of credibility.

The findings were analyzed using JBI's pragmatic meta-aggregative approach ¹⁷. Findings from across the studies were reviewed and grouped together based on similarity in concepts/meanings. Categorization involved the aggregation of the findings to generate a set of categories that represent common meanings. The quality of the findings was taken into account by considering their relative importance in shaping the core constructs of the category. Only findings rated unequivocal [U] or credible [C] were used to develop the meta-synthesis (Table 4). Categories were then compared, contrasted and synthesized further to produce a set of synthesized findings, defined as an "overarching description of a group of categorized findings that allow for the generation of recommendations for practice" ¹⁸. The meta-synthesis process was led by one reviewer. This was an

iterative process, involving review of the findings/categories/synthesized findings, going back to the original papers for clarification where necessary, and discussion with the whole team until agreement was reached. The ConQual tool was used to establish confidence in the synthesised findings¹⁹.

Results

A total of 317 studies were identified (300 from the database searches and as is commonly reported in qualitative reviews²⁰, an additional 17 from references of studies). A total of 54 duplicates were automatically removed from the 300 references. After reviewing the titles and abstracts of 263 studies, the full text of 23 studies was reviewed of which 16 studies (14 separate research studies) were included. (Figure 1). The characteristics of the included studies can be found in table 1.

Nine studies were conducted in the UK^{21, 22, 23, 24, 25, 26, 27, 28, 29}, three in the USA^{30, 31, 32} and two^{33, 34, 35} in Australia.

Only three studies included keratinocyte carcinoma^{21, 22, 32}. Two studies included melanoma that had relapsed^{27, 25}, two studies included stage I-III melanoma^{31, 28} and one study included stage III melanoma³⁵. In two studies, the stage of melanoma was unknown^{26, 24}. One study looked at intra-family risk communication³⁰, one study included views on a GP led follow up clinic²³ and one study looked at patient satisfaction with follow up care³³

The overall quality of the studies was good (Table 2), however only two studies^{25, 26} located the research culturally or theoretically and only one²⁶ reported the influence of the researcher on the research, indicating poor reflexivity overall for the included studies.

Main findings of the review

There were 153 findings, which were either unequivocal or credible. These findings were aggregated into 15 categories. The 15 categories were then meta-aggregated into four synthesized findings. See Table 3 for a summary of the meta-synthesis and Table 4 (supplementary files) for a full version. Key concepts within their constituent categories are illustrated using representative textual excerpts from selected findings (Table 5). The synthesised findings emerged from the data, and clustered around the natural time points used by the studies to collect data and also from the representation of study participants.

Synthesised finding 1: The time of diagnosis

Diagnosis is a time of shock and distress, where patients have significant support and information needs irrespective of the type of skin cancer. For many patients, this diagnosis can come as a severe shock, especially for those who believe their symptoms are relatively mild and therefore nothing to worry about.

Patients particularly remembered the use of the term 'cancer' as causing a significant shock.

...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)... (Winterbottom 2004, p229, BCC)

Their immediate distress impacted on their ability to listen and to be responsive to information given by the clinician at that time of diagnosis. Patients reported not remembering receiving information at this stage.

I was so upset about the diagnosis that I don't think much information would have penetrated because I was too focused on thinking I've got cancer because you seem to, I went into a, like a shocked of my own and switched off I think. (Moore 1996. p60, M)

Waiting for biopsy results caused considerable fear and anxiety for many patients. They felt that they were left to guess about their prognosis and the possible seriousness of their skin cancer. However once the results were known, many patients felt less anxious, regardless of the result and were able to adjust to their condition.

.....but it's the initial wait, the first, when you see the doctor until you have the first operation, the waiting and not knowing, you know...that's the worst part about it, it is the waiting and not knowing. (Moore 1996. p62, M)

Patients also expressed a need for emotional support. In some cases, healthcare providers gave patients the impression that skin cancer was less important than other types of cancer and, therefore they underestimated or ignored patients' emotional needs.

....And then, I can't say I'm feeling down today or whatever, I'm going to [cancer hospital] on Monday, I feel a bit crap today and all that. But you can't, I mean, if you knew somebody on the phone or you were going to [cancer hospital] and you could have half an hour.... But there's nothing, you're just out on a limb really. Even though it's a cancer, there's no actual help type thing (Stamataki 2015, p782, M stage IIIc)

Synthesised finding 2: The time around treatment and immediately afterwards.

For the time around treatment and afterwards, the experience of having skin cancer varies depending upon the type, stage and treatment. The impact of a skin cancer diagnosis can have significant emotional, physical, social and financial impact, some of which can be long lasting, and for which patients and their families may need support. Patients cope with their experiences in a variety of ways.

The treatment journey was often depicted as stressful and emotional for patients, associated with negative experiences such as the complications of cancer treatments, poor communication with treatment team members, not receiving adequate information and the uncertainty of not knowing if they would get back to how things were before. For some, there was also the need to travel long distances for treatment.

I'd say stress related to the cancer is the most bothersome and biggest issue...there's an unknown component whether it's going to heal or not and whether it's going to leave physical scars or not. (Steenrod 2015. p193, non-advanced BCC)

... 'I have struggled to move away from that time in hospital. I found it very difficult. I don't think in any way I was prepared for what it would do physically. The seriousness of it and the debilitating effect of the surgery was far more than I thought it was going to be' (Stothers 2015. p34-35, M)

In some cases, skin cancer patients expressed negative feelings about an altered body image resulting from treatments such as surgery and chemotherapy. This had psychological impacts on the patients and often disrupted their social interactions.

Uh, I'm tired of having my body cut. I mean, you could say it's at times mildly depressing (Steenrod 2015, p194, non-advanced BCC)

: "I was really shocked at what the operation had done. It was really disfiguring ... When you're disfigured in any way it takes a toll psychologically. (Tan 2014. p17, M stage III)

Having a skin cancer impacted on family and social life and some patients reported feeling unsupported by their family and/or employer.

... But your managers, you know, like I'd go in and say 'oh I'm really struggling at the minute, can you take, I can't do this, I need a bit of a, some weight taken off me at work' and they'll do it for a short period of time while you're in distress but then it's soon back on you isn't it? (Stamataki 2015. p784, M stage Ib)

Financial costs associated with travel, accommodation and treatment were sometimes an issue. Retaining health care and life insurance was important for young melanoma survivors in American studies.

'I mean and then what do you do if you can't get health insurance? I'll have to take a lousy job that I don't want to work at so that I'll have health insurance. Yeah, that's actually a huge fear for me.' (Oliveria 2013 p.111, M stages I to III)

Patients developed a range of mechanisms to cope with their cancer, including avoidance, positive re-framing, sticking to routines, seeking social support and solace from religious faith.

I have to say 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 (Winterbottom 2004. P230, M)

One study²⁵ focused particularly on patients who had transitioned from initial diagnosis of melanoma to nodal relapse. These patients used coping skills learnt from their initial diagnosis to help with a diagnosis of nodal relapse.

Physically I was aware of the signs of recurrence and psychologically I found it easier to cope, as opposed to the initial diagnosis which was a major 'shock' (Stothers) 2015. P34, nodal relapse of melanoma)

Synthesised finding 3: The time after treatment and the follow up period

Skin cancer survivors and their families may have ongoing support, information and risk management needs. The survivorship phase can be a period of liminality, characterised by fear and uncertainty, related to the possible, yet

uncertain, risk of skin cancer recurrence. Patients' care and information needs during skin cancer survivorship include the need for being able to identify, prevent and manage further risk for themselves and for the family. However many patients reported a lack of information.

Both keratinocyte carcinoma and melanoma patients described an ongoing sense of uncertainty and fear (being in limbo) associated with the possibility of recurrence of the skin cancer. This fear was exacerbated by inadequate knowledge about risks of recurrence and about when/how to seek help.

Well, it's just that, you know, I just hope that it's all gone and that it's not going to flare up again. I mean, I'm touching wood, I don't think it will do because I don't think it was that sort of thing, but there's bound to be doubts, small doubts, you know, even though people do try and reassure you. But hopefully everything will be okay. (Bath-Hextall 2013. p7, BCC)

I just feel like it's a sword hanging over my head. I guess because you are always keeping an eye on things, it's always there—it's like an undercurrent in your life. (MacLoone 2013. p1106, M)

The risk of me having another occurrence of melanoma is probably greaterand that is frightening. (McLoone 2013. P1997, M)

Many patients reported engaging more proactively in risk minimisation by using sun avoidance measures and undertaking regular skin self-examination. Some patients felt they had insufficient knowledge/information on how to self-monitor and what to look for.

Because to be quite honest I have had no literature about my melanoma, I have asked for booklets but there's never been any in the hospital and none's been sent out to me (Hall 2014.p1668, M)

I wasn't really given any advice on checking it at all. You know, I was just told that it was sun damage on my face and on my nose but I wasn't given any advice on how to check it. I mean I know, I've read up a lot about it, so I know that I check and then if there's things I can't see like my back, I get my husband to check, and I always check his regularly as well (Bath-Hextall 2013. p8, BCC)

I am [checking], yes, but I'm not too sure what to look for.... Now if I see anything that's not, I'll be, instead of waiting I shall be straight to the doctor's and see what it is. (Bath-Hextall 2013. p7, KC)

The presentation format of this information was limited and not always helpful: About my recurrence, they gave me percentages; anyway it was kind of alarming. Wasn't sure what it meant. (Loescher 2009. p303, M)

Um, the only change in lifestyle that I've done, as a result of the cancers, is I am much more aware of being in the sun without some sort of protection. (Steenrod 2015. p194, non-advanced BCC)

For some patients, their experience led to an increased concern for family and community members about their risks of skin cancer. In some cases, patients would actively educate others and encourage treatment seeking and preventive measures.

One or two people I have spoken to and I've said, I did say look out for dubious looking spots

and things that won't go away with ointments and things. (Bath-Hextall 2013. p7, KC)

Some participants perceived that family members had frank discussions about melanoma prevention and detection activities. For example, family members persistently reminded each other about sun safety in discussions of sun avoidance and shielding (e.g., sunscreen application and use of sun-protective clothing). (Loescher 2009. p6, M)

Synthesised finding 4: Satisfaction with skin cancer care and confidence in healthcare providers

Satisfaction with skin cancer care is influenced by the perceived competence of the relevant healthcare providers and by the structure and organisation of service provision. Health professionals can assist patients during treatment and beyond through clear and open communication, a caring approach and by providing support for positive coping strategies.

Some melanoma patients found the clinical settings unsuitable (e.g. overcrowded or lacking in privacy), which impacted on how they interacted with their healthcare providers. Some patients were particularly unhappy about long waiting times and limited consultation periods which hindered their ability to seek reassurance and information. In some settings, patients objected to frequent follow-up visits as these disrupted everyday life.

[Describing a follow-up at hospital]. "At it was bedlam, about 30 people in the waiting room. It just seemed like a cattle market, you know, can you understand what I mean. Every few minutes one was coming in and one was coming out." Patient 10. [...] "It's pretty drab and oppressive really. It doesn't seem to have had a lick of paint since the seventies." (Murchie 2010. p230, M)

Patients were satisfied with providers who they perceived to be clinically knowledgeable and who treated them in a holistic manner with compassion and empathy. Where either of these facets was missing, care was perceived as sub-optimal.

[A patient whose Dermatologist had misdiagnosed the cancer]: 'And there's a lot of ignorance around. Doctor says something, you think that's it. I was very ignorant with that first melanoma... (Oliveria 2013. p111, M)

"I don't want the comments anymore, if I have another medical student who says, 'Oh my gosh, you really had five melanomas. 'I don't want that anymore.'" (Loescher 2009. p304, M)

Melanoma patients in a GP-led follow up study had less confidence in the GP as compared to their hospital doctor and needed reassurance that they had undergone additional training. However they did feel that they were getting more detailed and comprehensive consultations as compared with the hospital appointments.

"When I went to her she spoke about having all the information, but she kept having to look up bits of paper. I just got the impression she wasn't 100% clued up about what was going on. At the hospital I felt they knew these things as a matter of course." (Murchie 2010. p230, M)

"He takes that bit more time. I was given a top to toe examination on both occasions and I felt I was getting a better return from him than I got from the hospital" (Murchie 2010. p229, M)

Discussion and recommendations

The previous systematic review in 2010 ¹⁰, highlighted the need for further research into the needs and experiences of skin cancer patients. Six years later a further 12 studies have been published, however only two of these studies exclusively considered keratinocyte carcinoma ^{21, 30}. Despite the high incidence rates of keratinocyte carcinoma worldwide ¹, very few studies have directly investigated the psychosocial effects of this cancer and its treatment.

The synthesized findings from this review provide new insights into the complexities and challenges of a patient who is diagnosed and treated for a skin cancer however still very few studies focus on the most common cancer in humans (keratinocyte carcinoma) and therefore an area for further research.

At diagnosis, despite the fact that keratinocyte carcinomas and melanomas can have very different prognoses, health professionals need to be sensitive to, and acknowledge, that having a diagnosis of *any type* of skin cancer often causes distress. The review shows that all patients require support and understanding, together with tailored information. Studies of other cancer types report similar conclusions ³⁶.

The time around treatment and immediately afterwards can be very different for skin cancer patients depending upon their treatment, type of cancer and stage. This is a time where there is a requirement for clear information that is tailored to the needs of the individual. Patients also need to be followed up by healthcare professionals who are not only clinically knowledgeable but show compassion and an understanding of the patient's psychosocial needs.

The review has shown that the follow up period can be experienced as a time of considerable uncertainty and fear especially around prognosis and recurrence. These findings are consistent with issues identified in a systematic review that looked at the unmet supportive needs of people with cancer ³⁷ and other studies in other cancer types ^{38, 39}.

Patients require clear supportive information about surveillance and risk management and this should include being able to identify skin changes, prevent and manage further risk - not just for themselves but also their family. Knowledge about recognising signs of skin cancer is particularly important since 44% of patients with a Keratinocyte Carcinoma will develop additional lesions within 3 years ⁴⁰ and there is a 2.8% risk of developing a second melanoma after five years and a 3.6% risk after 10 years ⁴¹. Other quantitative studies have also shown that patients with keratinocyte carcinoma experience anxiety and worry about future skin cancers ⁴², and have unmet needs regarding health system and information matters ⁸.

Level of confidence in the synthesised findings

The overall methodological quality of the included studies was good, although there was general poor reflexivity. Giving an overall score for the level of confidence in qualitative review findings is a relatively new development ^{43, 19}, and draws upon the concepts of dependability (established using a set of critical

appraisal questions) and credibility (ranked according to the 'goodness of fit' between the author's interpretation and the original data). Therefore there will always remain an element of subjectivity in assigning a level of credibility. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings. The overall dependability and credibility of all synthesised findings were therefore downgraded by 1 level and the overall ConQual score was medium (Table 6).

Limitations:

The review included 14 studies representing only 4 countries and therefore care must be taken in generalising the results of this review to other countries. In particular the category 'financial concerns and consequences' only applies to the USA and other countries with similar health systems.

Search strategies for qualitative research are less developed compared to quantitative research and therefore the main limitation of this review is that the search strategy may not have captured all relevant qualitative studies¹⁵.

Conclusion

This review has shown that, for many patients, having a skin cancer marks the start of a journey. The review shows that specific needs and experiences will vary at each stage depending upon the type of cancer and severity. Crucially, the review highlights how this journey does not end for patients with the cessation of treatment, but continues into an uncertain future requiring ongoing self-monitoring and often accompanied by fear and uncertainty around the identification of new skin abnormalities.

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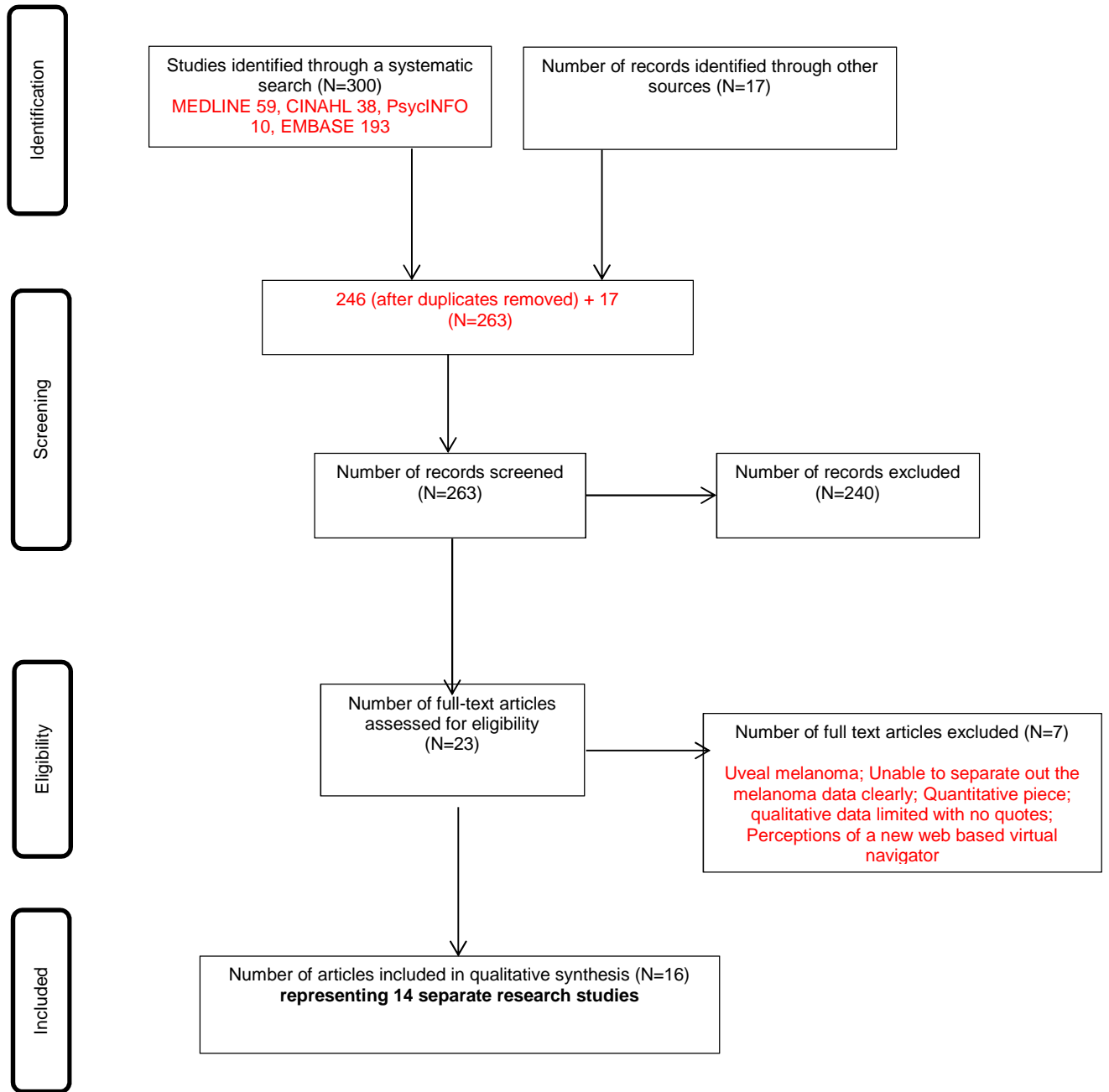


Figure 1: Search flow diagram

Liberate A, Altman DG, Tetzlaff J, Mulrow C, Gotzsche PC et al (2009) The PRISMA Statement for Reporting Systematic Reviews and Meta-Analysis of Studies that evaluate health care interventions: Explanation and elaboration. *PLoS Med* 6(7):e10001000. Doi:10.1371/journal.pmed.1000100

Table 1: Characteristics of included studies

Study & Setting	Methods	Participants	Data analysis	Phenomenon of interest
Bath-Hextall (2013) UK	Mixed methods study Semi structured interviews conducted over the telephone with the exception of one face to face interview Interviews were conducted at 4 time points: diagnosis, treatment, 8 weeks post treatment and one year post diagnosis	77 Participants (BCC and SCC) attending a skin cancer clinic and with a new clinical diagnosis of non-melanoma skin cancer. 15 participants were interviewed Mean age 70 years (range 35-89)	Thematic analysis	The needs, experiences and knowledge of individuals with Non Melanoma Skin Cancer (NMSC) from diagnosis up until one year
Loescher (2009) USA (two papers)	In-depth interviews separately for melanoma patients and for family members	11 participants with newly diagnosed melanoma and with a family history of melanoma recruited from the Cutaneous Oncology Program (COP) Age range (18-65 years)	Content analysis	High-risk family members' perceptions of healthcare provider communication regarding risk and risk modifying behaviours and recommendations for enhancing such communication
McLoone (2013) Australia (2 papers)	Semi-structured telephone interviews of participants who were at the follow up stage	20 high risk melanoma participants (9 male, 11 female recruited via the clinical database of the High Risk Clinic (HRC) and who had attended a minimum of three clinical consultation at the HRC. High risk defined as multiple diagnoses of primary invasive melanoma, or diagnosis of one primary invasive melanoma in addition to dysplastic nevus syndrome. Participants on current active treatment for locally advanced or metastatic melanoma were excluded. Mean age 57.6 years	Content analysis	Satisfaction with clinical care among individuals at high risk of developing melanoma, while receiving best practice follow-up care at a highly specialized melanoma clinic
Murchie (2010) UK (Scotland)	Semi-structured telephone interviews	18 melanoma participants (10 male, 8 female) whose melanoma had been surgically excised and were recurrence free. Age range (24-82) years	Thematic analysis	Practical experiences and feelings of people with cutaneous malignant melanoma about receiving structured melanoma follow-up from their

				general practitioner (GP) as an alternative to traditional hospital-based follow-up
Oliveria (2013) USA	8 focus groups	Follow-up (1-10 years) of 48 melanoma survivors (18 male, 30 female) attending the memorial Sloan-Kettering Cancer and who had invasive primary cutaneous melanoma stages I-III. Age range (26-90) years	Thematic text analysis	Experiences of melanoma survivors regarding sun protection, surveillance practices, psychosocial and family concerns
Stamatakis (2015) UK	Semi-structured interviews in a location convenient to the participants, in the study hospital or in the patient's home	15 participants (8 females, 7 males) with melanoma stages I to III and between 3 months to 5 years post diagnosis. Recruited from large specialist cancer referral and research centre. Age range (27-78) years	Thematic analysis	Impact of melanoma diagnosis on the supportive care needs of patients with cutaneous melanoma
Stothers (2015) UK	Semi-structured interviews conducted in a quiet room when they were attending for outpatient review appointments	6 melanoma participants (2 male, 4 females) diagnosed with nodal relapse of melanoma and at least 4 weeks post-block dissection of neck, axilla or groin for nodal relapse of melanoma within the last two years. Recruited from consultant plastic surgeons clinic. Age range (31-60) years	Thematic analysis	Patients' information and support needs when diagnosed with nodal relapse of melanoma and their experiences of the changing nature of coping with nodal relapse
Taylor (2009) UK (Wales)	Semi-structured interviews	10 males presenting to dermatology department with having been referred by GP for suspect melanoma	Content analysis	Men's perception of malignant melanoma
Winterbottom (2004) UK	Semi-structured interviews conducted in a consulting room at the dermatology centre	16 participants at different stages in the disease trajectory (5 malignant melanoma, 4 squamous and 7 basal cell carcinoma), recruited from a dermatology clinic. Mean age 63.8 years (34-90 range) Interviews took place 3-48 months post diagnosis (mean 8 months and 1 week)	Thematic content analysis	Experience of diagnosis and treatment of skin cancer
Tan (2014) Australia	Semi-structured interviews	19 participants diagnosed with stage III melanoma and free of disease recurrence at their most recent follow-up (10 female, 9 male) attending Melanoma Institute of Australia, a multidisciplinary melanoma research and treatment center. Mean age 58 years, SD 14 (range 30-82)	Thematic analysis	Psychosocial impacts experienced by stage III melanoma patients (and caregivers) throughout the course of the disease, and the coping responses they utilised in an attempt to promote psychosocial adjustment

Moore (1996) UK	Semi-structured in-depth interviews	7 patients melanoma (3 men and 4 women) attending a plastic surgery outpatient department in a district teaching hospital. Age range 34-76 years	Content analysis	Information needs of patients who are diagnosed with malignant melanoma and treated on an outpatient basis
Clarke (2006) UK	Semi-structured interviews during treatment and follow-up	11 melanoma patients (6 men and 5 women) receiving treatment at a large teaching hospital, UK, for a first relapse of malignant melanoma	Thematic analysis	Perceptions of available support services, preferences for source and type of support, and satisfaction with information and emotional support provided by staff
Steenrod (2015) USA	Cross-sectional study using semi-structured telephone interviews	34 patient interviews were conducted on newly diagnosed or recurrent BCC patients. Group 1 comprised of 11 patients with superficial subtype and 2 patients with nodular subtype BCC. Group 2 comprised 12 patients with metastatic BCC and 9 patients with locally advanced BCC. Patients were recruited from three clinical sites in the USA over a 10-month period.	Content analysis	Symptoms, impact of symptoms, and the health-related quality of life (HRQL) impact of BCC on the daily lives of patients across different stages of the disease To compare descriptively the experiences, symptoms, and HRQL impact of patients with non-advanced BCC with those of patients with locally advanced or metastatic disease
Hall (2014) UK (Scotland)	Semi-structured interviews were conducted, either face to face or on the telephone	21 participants (37-83) receiving structured follow up for melanoma	Thematic analysis	Views on the use of digital technology during follow-up and identify barriers or facilitators

Table 2. JBI-QARI critical appraisal for included studies

Studies	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Dep
Bath-Hextall 2013	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Hall 2014	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Loiselle 2013	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
McLoone 2013	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Loescher 2009 – same study as Loescher 2009 (a)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Murchie 2010	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Oliveria 2013	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Stamataki 2015	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Stothers 2015	U	Y	Y	Y	Y	Y	N	Y	Y	Y	↔
Taylor 2009	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Winterbottom 2004	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
McLoone 2012	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Tan 2014	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Moore 1996	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	↔
Clarke, S. A., et al. (2006)	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Steenrod, A. W., et al. (2015)	U	Y	Y	Y	Y	N	N	Y	Y	Y	↓
Criteria (Y=yes, N=no, U=unclear, Dep=Dependability grade) Q2,Q3,Q4,Q6 and Q7 are questions for judging dependability Arrow horizontal = the findings remain unchanged Arrow down = move down one level											

Table 3. Synthesized findings and categories

Synthesized Finding	Categories
<p>Synthesised finding 1: The time of diagnosis Diagnosis is a time of shock and distress, where patients have significant support and information needs irrespective of the type of skin cancer. For many patients, this diagnosis can come as a severe shock, especially for those who believe their symptoms are relatively mild and therefore nothing to worry about.</p>	<ul style="list-style-type: none"> • Shock • Fear and distress • Needing emotional support • Needing information and clear communication
<p>Synthesised finding 2: The time around treatment and immediately afterwards For the time around treatment and afterwards, the experience of having skin cancer varies depending upon the type, stage and treatment. The impact of a skin cancer diagnosis can have significant emotional, physical, social and financial impact, some of which can be long lasting, and for which patients and their families may need support. Patients cope with their experiences in a variety of ways.</p>	<ul style="list-style-type: none"> • An emotional journey • Physical consequences • Changes to body image • Social and relational changes and impacts • Financial concerns and consequences • Coping
<p>Synthesised finding 3: The time after treatment and the follow up period Skin cancer survivors and their families may have ongoing support, information and risk management needs. The survivorship phase can be a period of liminality, characterised by fear and uncertainty, related to the possible, yet uncertain, risk of skin cancer recurrence. Patients' care and information needs during skin cancer survivorship include the need for being able to identify, prevent and manage further risk for themselves and for the family.</p>	<ul style="list-style-type: none"> • Being in limbo: on-going fear and uncertainty • Self-monitoring • Understanding and communicating risk
<p>Synthesised finding 4: Satisfaction with skin cancer care and confidence in healthcare providers Satisfaction with skin cancer care is influenced by the perceived competence of the relevant healthcare providers and by the structure and organisation of service provision. Health professionals can assist patients during treatment and beyond through clear and open communication, a caring approach and by providing support for positive coping strategies.</p>	<ul style="list-style-type: none"> • Structure and follow up services • Competence, clinical knowledge and compassion

Table 4. Synthesized findings and categories

Synthesized Finding	Categories
<p>Synthesised finding 1: The time of diagnosis Diagnosis is a time of shock and distress, where patients have significant support and information needs irrespective of the type of skin cancer. For many patients, this diagnosis can come as a severe shock, especially for those who believe their symptoms are relatively mild and therefore nothing to worry about.</p>	<ul style="list-style-type: none"> • Shock • Fear and distress • Needing emotional support • Needing information and clear communication
<p>Synthesised finding 2: The time around treatment and immediately afterwards For the time around treatment and afterwards, the experience of having skin cancer varies depending upon the type, stage and treatment. The impact of a skin cancer diagnosis can have significant emotional, physical, social and financial impact, some of which can be long lasting, and for which patients and their families may need support. Patients cope with their experiences in a variety of ways.</p>	<ul style="list-style-type: none"> • An emotional journey • Physical consequences • Changes to body image • Social and relational changes and impacts • Financial concerns and consequences • Coping
<p>Synthesised finding 3: The time after treatment and the follow up period Skin cancer survivors and their families may have ongoing support, information and risk management needs. The survivorship phase can be a period of liminality, characterised by fear and uncertainty, related to the possible, yet uncertain, risk of skin cancer recurrence. Patients' care and information needs during skin cancer survivorship include the need for being able to identify, prevent and manage further risk for themselves and for the family.</p>	<ul style="list-style-type: none"> • Being in limbo: on-going fear and uncertainty • Self-monitoring • Understanding and communicating risk
<p>Synthesised finding 4: Satisfaction with skin cancer care and confidence in healthcare providers Satisfaction with skin cancer care is influenced by the perceived competence of the relevant healthcare providers and by the structure and organisation of service provision. Health professionals can assist patients during treatment and beyond through clear and open communication, a caring approach and by providing support for positive coping strategies.</p>	<ul style="list-style-type: none"> • Structure and follow up services • Competence, clinical knowledge and compassion

Table 5. CATEGORIES AND REPRESENTATIVE QUOTES

Categories	Representative quotes
<p>Shock</p>	<p>I was so upset about the diagnosis that I don't think much information would have penetrated because I was too focused on thinking I've got cancer because you seem to, I went into a, like a shocked of my own and switched off I think. (Moore 1996. p60, M)</p> <p>I went very quiet for the first fortnight afterwards... of course I was panicking for 14 days...and then when he turned around and said you have got it all (the Malignant Melanoma was completely excised) but we are going to take a precaution now (and excise a further 1–2cm) and that was a relief, that first fortnight, every time I had nothing to do I would sit down and start thinking, what if. (Taylor 2009. p33, M)</p> <p>...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. (Winterbottom 2004. p230, M)</p> <p>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. (Winterbottom 2004. p230, M)</p> <p>...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)... (Winterbottom 2004, p229, BCC)</p> <p>It's very confusing ... You're going from doctor to doctor ... They're all saying things at you ... and you're just sitting there going 'I've got cancer' ... you are definitely not taking anything in. (Tan 2014. p11, M stage III)</p> <p>You know, to the person who has actually got it it's not relatively minor... it's that big C word again, and while it's there it can spread. But that's a personal feeling of mine and I don't know how many people are diagnosed with this type of thing yearly but I bet most people feel the same. (Bath-Hextall 2013. p6, KC)</p> <p>Physically I was aware of the signs of recurrence and psychologically I found it easier to cope, as opposed to the initial diagnosis which was a major shock (Stothers 2015. P34, M with nodal relapse)</p>
<p>Fear and distress</p>	<p>Um, there are one or two things that I have thought about, um, perhaps I've been lucky, in my opinion, it hasn't been very long, I don't know, but it's the initial wait, the first, when you see the doctor until you have the first operation, the waiting and not knowing, you know...that's the worst part about it, it is the waiting and not knowing. (Moore 1996. p62, M)</p> <p>Over the fortnight while I was waiting for the results I had some really bad days when I thought gosh I'm not going to be here in six months' time. (Moore 1996. p62, M)</p>
<p>Needing emotional support (Emotional needs at diagnosis)</p>	<p>Immediately around the time of being biopsied and finding the results, I'd say that for me is pretty severe. Now I'm just sort of waiting to get through the process and then it's going to be very stressful the day of the surgery and the day after for sure ... (Steenrod 2015, p193, non-advanced BCC)</p> <p>...and then, I can't say I'm feeling down today or whatever, I'm going to [cancer hospital] on Monday, I feel a bit crap today and all that. But you can't, I mean, if you knew somebody on the phone or you were going to [cancer hospital] and you could have half and hour..... But there's nothing, you're just out on a limb really. Even though it's a cancer, there's no actual help type thing (Stamataki 2015, M stage IIIc)</p> <p>There're just so many people that don't understand how dangerous [melanomas] are. Like I've had many people say, "Oh you've just had a mole removed," and I'm like, "It's actually cancer, believe it or not." So yeah, there's a wrong perception from most people. The actual depth of what one is I think is missed. (McLoone 2012. pp1108-1109, M)</p> <p>I definitely think there's something in positive language regardless of whether it's the right think to do or whether people see you coming back with cancer. There is definitely something about giving somebody a positive message. Albeit for that time (Stothers. P35, Melanoma relapse)</p>

<p>Needing information and clear communication</p>	<p>Maybe a little bit more information about what the scar would feel like and look like’ (Bath-Hextall 2013. p7, BCC)</p> <p>...but it’s all these stages and we didn’t have a clue...but you couldn’t ask anybody, you know, go back to them and say; cause you don’t keep like to say ‘well, I’ve been today to the thing [hospital] and they said stage three’. Well, what does stage three mean? (Stamataki 2015. p785, M stage IIIc)</p> <p>When I go to the clinic I don’t seem to be, I don’t seem to be picking up just what the situation is, you know, what I can expect for the future, what will the next stage be? What will be the next thing to happen? (Stamataki 2015. p785, M)</p> <p>...there was [consultants name] gave me a little thing about the thing to start off with. You know, on the very first day there was a pack of things and sort of nice pictures and good information and so on....but it was day one, here’s your package , erm, and that’s everything finished...there was o further information added in, after the op and things like that.. Yes, they talked a little bit about it but if someone’s telling you you’re going to have a fairly major operation, not everything goes in... (Stamataki 2015, p786, M)</p> <p>He is probably a brilliant surgeon but he was certainly no communicator ...we were both scared to ask questions because he answered them with one word (Tan 2014. P12, M)</p>
<p>An emotional journey</p>	<p>Nobody rings me up and says ‘How are you going?’, ‘Are you feeling all right?’ I suppose they’ve got so many they can’t remember everybody.” (Tan 2014. p15, M stage)</p> <p>I had no idea how to put [the stocking] on. I had no understanding of lymphedema. (Tan 2014. p12, stage III M)</p> <p>Oh look, I couldn’t care less about scarring. I would rather a scar than, you know, be dead. (MacLoone 2012. p1106, M)</p> <p>When I don’t think I’m going to be out and I end up having to be out, you get stressed. Like I’m outside for a half hour and I’m like, “I’ve got to get out of the sun. I don’t have anything on. (Oliveria 2013. p111, M)</p> <p>I’d tend to find the sadness in everything ... I did have a few times there where I was so depressed I probably did go a little bit suicidal ... thoughts would be running through your mind, ‘If I’m going to die, just let it happen really quickly rather than dragging on. (Tan 2014. p17, M stage III)</p> <p>I was just snapping at everyone because I was so frustrated I couldn’t get up and do it myself ... it was very, very frustrating, just not being able to do a normal, everyday, simple thing, even down to bathing. (Tan 2014. pp16-17, M stage III)</p> <p>I’d say stress related to the cancer is the most bothersome and biggest issue...there’s an unknown component whether it’s going to heal or not and whether it’s going to leave physical scars or not. (Steenrod 2015. p193, non-advanced BCC)</p> <p>Probably – at this point, probably the stress of the unknown because I know the itching will go away and the redness will go away. (Steenrod 2015, p 193, locally advanced and/or metastatic BCC)</p> <p>Uh, I’m tired of having my body cut. I mean, you could say it’s at times mildly depressing .(Steenrod 2015, p194, non-advanced BCC)</p>
<p>Physical consequences</p>	<p>...‘I have struggled to move away from that time in hospital. I found it very difficult. I don’t think in any way I was prepared for what it would do physically. The seriousness of it and the debilitating effect of the surgery was far more than I thought it was going to be’ (Stothers 2015. p34-35, M)</p> <p>I’m an active person, I play tennis and I surf, I’m always swinging a golf club ... I was without my arm for quite a while and I didn’t know if it was going to come back, so it was pretty emotionally traumatising. (Tan 2014. pp12-13, M stage III)</p> <p>“I can’t walk the dog ... I don’t bend over in the garden for a long time because I can’t get back up ... I can’t have hot water on my legs so during the day I’ve got to shave [them] outside ... it’s about the simple things in life that you take for granted.” (Tan 2014. pp14-15, M stage III)</p> <p>Well, I’m stuck inside, like I said. I mean, I can jump in the car and go to the store and stuff. But I’m limited to doing normal things of going outside, maybe going to a, to a baseball game, or going to the park and just going...for a walk. I can’t do any of those things. (Steenrod 2015. p194, locally advanced and /or metastatic BCC)</p>

	<p>itching and, uh, itching and burning because that causes, when I rub that it causes it to bleed. You know, even if you rub on the side of it or something, uh, then the scab comes off. So the itching is what triggers it. (Steenrod 2015. p193, locally advanced and /or metastatic BCC)</p> <p>I'd say stress related to the cancer is the most bothersome and biggest issue....there's an unknown component whether it's going to heal or not and whether it's going to leave physical scars or not. (Steenrod 2015, p193, non-advanced BCC)</p>
<p>Changes to body image</p>	<p>I was really shocked at what the operation had done. It was really disfiguring ... When you're disfigured in any way it takes a toll psychologically. (Tan 2014. p17, M stage III)</p> <p>Well I don't know why I thought they would fill it in [the scar]...when I had the operation I was in bed...and they came to the great unveiling...she took the dressing off and they were all 'oh great' and all this that and the other...and I'm just looking...the nurse on the ward, she says to me 'are you alright?' I went 'well, to be truthful...they're all congratulating saying how great it is and all I can see is a dirty great crater'. She said 'did you not expect that?' I said 'no, I didn't'...I mean I'm not that bothered because the cancer's gone but it was a shock at the time. (Stamataki 2015. p783, M)</p> <p>I just don't know, and I just feel, like probably physical appearance is flawed a little bit... so I feel a little bit different about myself or how people see me, and it's daft because I know everybody says 'you're just the same'... and I am the same person...maybe I feel I've not met anybody or, you know, they might find me sort of less attractive because of this thing (Stamataki 2015. p783, M)</p> <p>Oh look, I couldn't care less about scarring. I would rather a scar than, you know, be dead. (MacLoone 2012. p1108, M)</p> <p>Well, I don't, I don't like it when people stare at me. Um, it makes me a little bit uneasy; especially the little children. That bothers me. (Steenrod 2015. p194, locally advanced and /or metastatic BCC)</p> <p>I was a little anxious because I didn't quite know what I was going to look like when I was finished (Bath-Hextall 2013.p7, BCC)</p> <p>Well, I wear a hat and the wig because after all these surgeries I- I have no hair, it's all scar tissue and [sigh] I think my mind has shut down (Steenrod 2015. p194, non-advanced BCC)</p>
<p>Social and relational changes and impacts</p>	<p>Well I've been married to the same person for 42 years, and I love him dearly, but he didn't do well with my diagnosis, which was two years ago. And it was a stage II, and it was a big—it was a fairly big deal. But for some reason he became sick when I got the diagnosis. It was almost as though I was getting more attention than he was, and this became a problem just because I sort of—I guess I'm sort of an insular person, and when this happened I sort of turned inward, and you're trying to steel yourself and get through this, and you just don't want to deal with—I don't want to deal with other people and their problems. I need to focus on this. And it's a selfish thing for me, I know that, but I couldn't deal with him. I never took him with me to the doctor because the first time I did I came out to the waiting room and there he is and he says, "Oh, I feel awful." Wait a minute, you know? I'm the guy with cancer, and you feel awful? So this was a problem for probably the first year. (Oliveria 2013. p110, M stages I-III)</p> <p>It's (hearing about increase likelihood of getting a new melanoma if you get pregnant) a disappointment. He (doctor) said there are studies showing that you can—so you're actually taking a personal risk by getting pregnant, not to mention that then that's a period of not being as vigilant, because I can't do some of the screens I was doing. So it's sort of just hard to put at odds having a family versus taking care of your own body.' 'I'm thirty-nine and between my age and the impact of getting pregnant with hormonal levels on melanoma—I think one of the things that's impacted me most significantly is that I've decided not to get pregnant. (Oliveria 2013. p111, (M stage I-III)</p> <p>...But your managers, you know, like I'd go in and say 'oh I'm really struggling at the minute, can you take, I can't do this, I need a bit of a, some weight taken off me at work' and they'll do it for a short period of time while you're in distress but then it's soon back on you isn't it? (Stamataki 2015. p784, M)</p> <p>It puts a black cloud above [your life] ... my husband's family is organising a family holiday next April ... it's very difficult to commit to that because I don't have a clue what's going to be going on. (Tan 2014. p13, M stage III)</p> <p>Yeah, I'm not as motivated, you know, I just I'm tired, uh, when you're not sleeping you don't have that energy to go to go out there and, and do those things [hiking with dog or going snowshoeing with friends]. I try to push myself too when I have a good days, but there's been a lot more bad days. (Steenrod 2015. p194, non-advanced BCC)</p> <p>What it did do, I think, more than anything else, was to make me understand the effects, of the</p>

	<p>impact it would have on other people in more serious cases (Winterbottom 2004. P231, M)</p> <p>I don't know if it's leisure, but it's basically all the yard wor. Back when they were open sores it would stop [me from] meeting people-talking to people and basically staying in . (Steenrod 2015. P194 locally advanced and /or metastatic BCC)</p> <p>In terms of my life, I think it just made me focus down on the day to day and not be so over whelmed with irritations at work...It's just- it's like it's not important. The fact that I'm alive another day is more important. (Oliveria 2013. P110, M stage III)</p>
<p>Financial concerns and consequences</p>	<p>I mean and then what do you do if you can't get health insurance? I'll have to take a lousy job that I don't want to work at so that I'll have health insurance. Yeah, that's actually a huge fear for me. (Oliveria 2013 p.111, (M stages I to III)</p> <p>It (my melanoma diagnosis) really didn't hit me until I went to apply for life insurance...it was the life insurance that made it hit home and there was a difference—I have a history that affected my life. (Oliveria 2013. p111, M stages I to III)</p> <p>I wouldn't want to go in another trial because I'd have to be in Sydney every three weeks and it's going to cost us 600 [dollars] every time we went ... and we just haven't got that money." (Tan 2014. p13, M stage III)</p>
<p>Coping</p>	<p>I'm still reasonably optimistic about the future. I am aware of how serious and life-threatening my disease is but I don't feel it's a tragic situation. If you plan to die you will die so my view of it is that I don't plan to die. I have chosen to live and the feeling of normality is very important in lifting you from a depressed feeling. (Stothers 2015. pp35-36, M with nodal relapse)</p> <p>I know it's not severe at all if you have it removed quickly. (McLoone 2012. p1106, M)</p> <p>...this diabetes that I got is more worrying, „cos you don't know what you can eat, what you can't eat... (Winterbottom 2004. p230, KC)</p> <p>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 (Winterbottom 2004. p230, M)</p> <p>There's some things you don't want to ask, some things you don't want to know about ... you can maintain a more positive outlook if you've got some kind of ignorance. (Tan 2014. p12, M stage I to III)</p> <p>Physically I was aware of the signs of recurrence and psychologically I found it easier to cope, as opposed to the initial diagnosis which was a major 'shock' (Stothers) 2015. P34, nodal relapse of melanoma)</p> <p>I [thought] 'I've just got to get up, I've got to start doing anything, I'm wallowing in self-pity here' ... So I got on to a personal trainer ... I just thought 'I have to take control of this situation. (Tan 2014. p14, M stage I to III)</p> <p>Family and friends have been absolutely amazing. My immediate family, I couldn't have done it without them ... my friends ... were absolutely amazing. They cooked and cleaned and continually did it for nearly six months. (Tan 2014. pp18-19, M stage I to III)</p> <p>My Christian faith definitely helped, that and the support of the church that we go to and knowing that lots of people were praying for me, and knowing that God was in control. (Tan 2014. p20, M stage I to III)</p>
<p>Being in limbo (Ongoing fear and uncertainty)</p>	<p>You know, to the person who has actually got it it's not relatively minor... it's that big C word again, and while it's there it can spread. But that's a personal feeling of mine and I don't know how many people are diagnosed with this type of thing yearly but I bet most people feel the same. (Bath-Hextall 2013. p6, KC)</p> <p>Well, it's just that, you know, I just hope that it's all gone and that it's not going to flare up again. I mean, I'm touching wood, I don't think it will do because I don't think it was that sort of thing, but there's bound to be doubts, small doubts, you know, even though people do try and reassure you. But hopefully everything will be okay. (Bath-Hextall 2013. p7, BCC)</p> <p>When I'd first come for the quarterly check-ups or whatever, I'd feel a little tense, realizing that I could walk out of here with a different answer, or my life could change. (Oliveria 2013. p111, M)</p> <p>The risk of me having another occurrence of melanoma is probably greaterand that is frightening. (McLoone 2013. P1997, M)</p> <p>It's weird cause you're always looking for lumps or moles...you're always conscious of it cause you're thinking is it another one? ...I mean I am good at checking but it's just there all the time it's</p>

	<p>like a curse on you type of thing. Yeah, even though you can't; I mean I think I'd sooner have treatment than just wait, you know like, cause it's like, not a death sentence but it's like, you're always worried that you are gonna find another lump but yeah, it never goes away, never...like you're in constant fear...And it never, never goes away and there's like, there's nothing you can do or like any treatment you can do. You're like waiting and waiting and waiting and that's all you're doing (Stamataki 2015. p782, M)</p> <p>I just feel like it's a sword hanging over my head. I guess because you are always keeping an eye on things, it's always there—it's like an undercurrent in your life (MacLoone 2013. p1106, M)</p> <p>Each time I get another one I have a real sense of, "Oh God, here we go again," and I wonder if this is going to be the one that gets me. It's not really a burden but it's kind of like a shadow I guess, and progressively it gets a little bit darker each time. . . . It's going to be this constant, I guess, worry or concern in my life. (MacLoone 2012. p1106, M)</p>
<p>Self-monitoring</p>	<p>I am [checking], yes, but I'm not too sure what to look for.... Now if I see anything that's not, I'll be, instead of waiting I shall be straight to the doctor's and see what it is (Bath-Hextall 2013. p7, BCC)</p> <p>I wasn't really given any advice on checking it at all. You know, I was just told that it was sun damage on my face and on my nose but I wasn't given any advice on how to check it. I mean I know, I've read up a lot about it, so I know that I check and then if there's things I can't see like my back, I get my husband to check, and I always check his regularly as well (Bath-Hextall 2013. p8, BCC)</p> <p>I'm only too happy to examine myself. You know it's my life on the line if I don't bother so I'm very happy to do it. (Murchie 2010. p229, M)</p> <p>So what I should have done right from the beginning was, as soon as I saw something like that, if they're not real sure, why not just get it taken off? And why don't you biopsy it or do something? So that taught me to be real proactive. If somebody says, "Well, don't worry about it," I'll tell you what, if it bothers me, I'm not going to take that for an answer anymore. I'm going to say, "Do something. I demand it. (Oliveria 2013. p110, M)</p> <p>The presentation format of this information was limited and not always helpful: About my recurrence, they gave me percentages; anyway it was kind of alarming. Wasn't sure what it meant" (Loescher 2009. p303, M)</p> <p>'I'm not a professional and I don't trust that I will pick up on any change. It's hard to work out what was [already] there. I've got so many moles'. [Male participant] (MacLoone 2013. p1197, M)</p> <p>Um, the only change in lifestyle that I've done, as a result of the cancers, is I am much more aware of being in the sun without some sort of protection. (Steenrod 2015. p194, non advanced BCC)</p> <p>This last appointment was the first time that I was asked to. Nobody had mentioned that I should be well I look at my moles, I keep an eye out because they are monitoring two others, I think there's nothing to do – it's just that they are slightly different. But this was the first time somebody had said to me that I should be checking under my arm for my lymph nodes. Nobody mentioned that before (Hall 2014.P1665, M)</p> <p>What my perception of what I should be looking for is obviously different from what one is actually looking for, because the one on my wrist, I would think twice about it , and yet Dr X said, 'that one's going to have to go' (Hall 2014.p1665, M)</p> <p>No, no I just leave that to the experts. (Hall 2014.p1666,M)</p> <p>But how can a lay person give a detailed explanation about melanoma, because I don't know what they look for. (Hall 2014.p1666,M)</p> <p>Because to be quite honest I have had no literature about my melanoma, I have asked for booklets but there's never been any in the hospital and none's been sent out to me (Hall 2014.p1668, M)</p> <p>I suppose It's more about having information about what melanoma means in relation to the likelihood of me having it again. What should I be looking for? (Moore1996. P67, M)</p>
<p>Understanding and communicating risk</p>	<p>One or two people I have spoken to and I've said, I did say look out for dubious looking spots and things that won't go away with ointments and things. (Bath-Hextall 2013. p7,BCC)</p> <p>...it has raised awareness significantly in our family now, yeah...I've been into town today and bought a moisturiser with SPF25 or something or other, so yeah. So I'll wear that constantly now rather than general moisturisers. (Bath-Hextall 2013. P 7, BCC)</p>

	<p>Our friends all know that they can't go anywhere outside with me unless they have put on sunscreen. We [family] are responsible for spreading the word. We owe this to ourselves and to others. (Loescher 2009. p6-7, M)</p> <p>...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. (Winterbottom 2004. p229, BCC)</p> <p>When I'm standing at an intersection I sort of find the shadow of a post," believing that even the smallest amount of sun exposure could trigger another melanoma. (MacLoone 2012. p1107, M)</p>
<p>Structure and follow up services</p>	<p>At it was bedlam, about 30 people in the waiting room. It just seemed like a cattle market, you know, can you understand what I mean. Every few minutes one was coming in and one was coming out." Patient 10. [...] "It's pretty drab and oppressive really. It doesn't seem to have had a lick of paint since the seventies. (Murchie 2010. p230, M)</p> <p>Parking is a nightmare; I'm always conscious of whether I've got enough money in the metre and if they're [i.e. the doctors] twenty minutes late, I could be late and I told them...if I get a parking fine I'm passing it onto you. (MacLoone 2013. p1998, M)</p> <p>...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. (Winterbottom 2004. p231, M)</p>
<p>Competence, clinical knowledge and compassion</p>	<p>The good thing is the bad stuff's gone and I'm not that vain, if you know what I mean. (Bath-Hextall 2013. p6, BCC)</p> <p>Some participants perceived passive and uncaring communication from providers: "I don't want the comments anymore, if I have another medical student who says, 'Oh my gosh, you really had five melanomas. 'I don't want that anymore. (Loescher 2009. p304, M)</p> <p>There's a very valid lack of communication in the whole process, because lots of people are intimidated and they won't ask the doctor, "What did you say, what does this mean, what can I do to correct this? (Loescher 2009. p304, M)</p> <p>The main disadvantage of GP-led follow-up was feeling less reassured, or having less confidence in their GP than in the hospital specialist. There was remarkable agreement amongst participants that in order for patients to gain maximum reassurance during a GP-led follow-up appointment, the GP needed to be friendly and known, have undergone extra training, appear receptive to questions and familiar with the study protocol and working explicitly to a clear structure. When some of these aspects were lacking, some patients reported feeling unhappy:</p> <p>When I went to her she spoke about having all the information, but she kept having to look up bits of paper. I just got the impression she wasn't 100% clued up about what was going on. At the hospital I felt they knew these things as a matter of course. (Murchie 2010. p230, M)</p> <p>I feel more in control with this system. I know what I'm looking for and if there's a problem or I'm worried, I just need to pick up the phone and I can get seen the same day. I couldn't do that before. (Murchie 2010. p229, M)</p> <p>The GP follow-up consultations were generally viewed as thorough, with many patients believing that they were more detailed and comprehensive than consultations provided in hospital: "He takes that bit more time. I was given a top to toe examination on both occasions and I felt I was getting a better return from him than I got from the hospital" (Murchie 2010. p229, M)</p> <p>Survivors believed it is important to find a dermatologist whom they perceive to be competent—some survivors had dermatologists who had missed their melanoma: 'And there's a lot of ignorance around. Doctor says something, you think that's it. I was very ignorant with that first melanoma... (Oliveria 2013. p111, M)</p> <p>...it's almost a case of 'right, turn, right, on the bed let's look at your leg. Oh, that's fine' you know, poke, poke, poke in the groin for any...swelling of the lymph nodes and 'okay, you're fine, come back in 3 months (Stamataki 2015. p786, M)</p> <p>I definitely think there's something in positive language regardless of whether it's the right thing to do or whether people see you coming back with cancer. There is definitely something about giving somebody a positive message. Albeit for that time (Stothers 2015. p35, M nodal relapse).</p> <p>The emotional side of things is not taken into account somehow. Even when you're on the treatment, it's "how are you feeling?" they're all physical symptoms of how you're feeling rather than, "is it getting you down emotionally? How are you dealing with it? (Clarke 2006. p69, M relapsed)</p> <p>I'm not the sort of person who goes into a great deal of discussion about how I feel emotionally. To me, I just want to come and get out as quickly as possible. So, yeah, I'm sure the support is there if I want it, but I don't particularly need it (Clarke 2006. p69, M relapsed)</p>

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Table 6. ConQual summary of findings

Systematic review title: The needs and experiences of people with a diagnosis of skin cancer Population: Adults (18 years and above) with skin cancer Phenomena of interest: Needs and experiences Context: All countries, all health care settings						
Synthesized findings	Dependability rating	Comment	Credibility rating	Comment	ConQual rating	Comment
Diagnosis is a time of shock and distress where patients have significant support and information needs	↓	Downgraded one level. All primary papers had clear articulation and fit of the methodology and methods employed, but the majority had poor reflexivity	↓	Downgraded one level due to a mix of unequivocal and equivocal findings	Moderate	The overall methodological quality is good although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings
The experience of having skin cancer varies depending upon the type, stage and treatment. The impact of a skin cancer diagnosis can have significant emotional, physical, social and financial impact, some of which can be long lasting, and for which patients and their families may need support. Patients cope with their experiences in a variety of ways	↓	Downgraded one level. All papers had clear articulation and fit of the methodology and methods employed, but the majority had poor reflexivity	↓	Downgraded one level due to a mix of unequivocal and equivocal findings	Moderate	The overall methodological quality is good although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings
Skin cancer survivors and their families may have ongoing support, information and risk management needs	↓	Downgraded one level. All papers had clear articulation and fit of the methodology and methods employed, but the majority had poor reflexivity	↓	Downgraded one level due to a mix of unequivocal and equivocal findings	Moderate	The overall methodological quality is good although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings
Satisfaction with skin cancer care is influenced by the perceived competence of the relevant healthcare providers and by the		Downgraded one level. All papers had clear articulation and		Downgraded one level due to a mix of unequivocal	Moderate	The overall methodological quality is good although there was

<p>structure of service provision. Health professionals can assist patients during treatment and beyond through clear and open communication, a caring approach and by providing support for positive coping strategies</p>	<p>↓</p>	<p>fit of the methodology and methods employed, but the majority had poor reflexivity</p>	<p>↓</p>	<p>and equivocal findings</p>		<p>general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings</p>
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Table 7. Search strategy for MEDLINE on Ovid

- 1 (melanoma adj1 skin).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 2 (non-melanoma adj1 skin).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 3 (non adj1 melanoma adj1 skin).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 4 (skin adj1 cancer).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 5 (basal adj1 cell adj1 carcinoma).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 6 (rodent adj1 ulcer).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 7 (squamous adj1 cell adj1 carcinoma).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 8 1 or 2 or 3 or 4 or 5 or 6 or 7
- 9 Carcinoma, Basal Cell/
- 10 Carcinoma, Squamous Cell/
- 11 9 or 10
- 12 8 or 11
- 13 needs.mp.
- 14 experiences.mp.
- 15 information.mp.
- 16 preference.mp.
- 17 13 or 14
- 18 15 or 16
- 19 12 and 17 and 18