The needs and experiences of patients with skin cancer: a qualitative systematic review with metasynthesis

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Summary

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. Our objective was to undertake a qualitative systematic review of the needs and experiences of people with a diagnosis of skin cancer. To update the previous review, the following databases were searched from 2010 to 30 November 2015: CINAHL PsycINFO, Medline and Embase. The methodological quality of the studies was assessed using the Joanna Briggs Institute Qualitative Assessment Review Instrument. The qualitative research findings were synthesized using a pragmatic meta-aggregative approach. A total of 14 studies (16 papers) were included. Only three studies included patients with keratinocyte carcinoma. Overall, 15 categories were identified and these resulted in four overarching synthesized findings (SFs) from diagnosis (SF1), throughout treatment (SF2) and follow-up (SF3), and then a fourth SF (SF4) that addressed patients’ satisfaction with their care and their relationship with healthcare professionals. Despite the fact that patients with keratinocyte carcinoma and melanoma can have a very different prognosis, they also share similar needs and concerns especially around the time of diagnosis and follow-up/surveillance for new lesions. Healthcare professionals working with patients with skin cancer need to understand their psychosocial concerns and their information needs in order to design services appropriately. Future studies need to consider patients with keratinocyte carcinoma in addition to patients with melanoma.

What’s already known about this topic?

- The incidence of skin cancer is high compared with 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 patients with skin cancer.

What does this study add?

- An additional 12 studies were identified, which focused primarily on melanoma.
- Diagnosis of any type of skin cancer can be distressing and the patient’s experience is dependent on its type and severity.
- Patients need emotional support and information tailored to the stage of their particular skin cancer journey. Their experience continues post-treatment, with an ongoing need for information about risk management and skin cancer detection.
Skin cancer is the most common cancer in humans and the incidence is increasing worldwide. There are two main types of skin cancer, namely melanoma and keratinocyte carcinoma. Keratinocyte carcinoma accounts for approximately 97% of skin cancers, which are either basal cell carcinomas (BCCs) or squamous cell carcinomas, along with some rarer types. Currently, 2–3 million keratinocyte carcinomas and 130 000 melanoma skin cancers occur globally each year and one in every three cancers diagnosed is a skin cancer (World Health Organization 2014, http://www.who.int/uv/factsheet/sun/en/index1.html). Skin cancer affects people from all communities and age groups. Although keratinocyte carcinoma is seen mostly in those aged over 50 years, increasing numbers of younger people are being affected. The large increase in skin cancer incidence, and the fact that keratinocyte carcinoma has high rates of recurrence and subsequent primaries, presents a significant challenge for all healthcare systems.

Patient needs and preferences comprise a core component of evidence-based medicine; however, the support needs and experiences of patients with skin cancer 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, https://www.nice.org.uk/guidance/csg8). Qualitative research is ideally suited to provide an in-depth picture of the needs and experiences of patients with skin cancer; however, until fairly recently, most empirical research has been quantitative in nature and has focused primarily on melanoma. In 2011, one of the authors of this paper (F.B.H.) published a qualitative systematic review and found only two studies that had examined the needs and experiences of people with skin cancer; however, until fairly recently, most empirical research has been quantitative in nature and has focused primarily on melanoma. In 2011, one of the authors of this paper (F.B.H.) published a qualitative systematic review and found only two studies that had examined the needs and experiences of people with skin cancer. Qualitative systematic reviews have an important role to play in terms of feasibility and acceptability of healthcare interventions. Recently, there has been increased interest in conducting qualitative research in dermatology and, therefore, an update of the previous review is timely in order to inform practice and improve the patient’s experience of having a skin cancer.

Materials and methods

This review adheres to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research guidelines and follows the Joanna Briggs Institute (JBI) methodology for qualitative systematic review. This is an update of a previous review. 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 the date of publication. Relevant keywords appropriate to the review objectives were identified following consultation with information specialists. The following databases were searched from 2010 to 30 November 2015: CINAHL PsycINFO, Medline and Embase. An example of the search strategy for Medline on Ovid is given in Table 1. In accordance with current methodological recommendations, this search strategy was designed to be sensitive rather than specific. The initial search results were exported to Endnote and duplicates were removed automatically. Studies identified from hand searching of reference lists were manually 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 articles for the relevant studies were obtained and assessed again. There was disagreement between the two reviewers for only one article 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). There were no disagreements and, therefore, no need to involve a third reviewer.

Data extraction utilized a standardized 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 the included studies, which were 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). These levels were assigned depending on the extent to which supporting quotes, detail and relevant context were available and gave support to the finding’s credibility, as per JBI guidelines (JBI handbook). The levels were assigned as follows:

- 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 were not supported by data.

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

The findings were analysed using JBI’s pragmatic meta-aggregative approach. Findings from across the studies were reviewed and grouped together based on similarity of 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 metasynthesis (Table 2). 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’. The metasynthesis process was led by one reviewer. This was an iterative process, involving a 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 synthesized findings.

**Results**

A total of 317 studies were identified (300 from the database searches and as is commonly reported in qualitative reviews and 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 (Fig. 1). The characteristics of the included studies can be found in Table 3. Nine studies were conducted in the U.K., three in the U.S.A. and two in Australia. Only three studies included keratinocyte carcinoma. Two studies included melanoma that had relapsed, two

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**Fig 1.** Search flow diagram.

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**Studies identified through a systematic search (n = 300)**
- Medline 59
- CINAHL 38
- PsycINFO 10
- Embase 193

**Number of records identified through other sources (n = 17)**

**Number of records screened (n = 263)**

**Number of full-text articles assessed for eligibility (n = 23)**

**Number of full text articles excluded (n = 7)**
- Uveal melanoma; Unable to separate out the melanoma data clearly; Quantitative piece; Qualitative data limited with no quotes; Perceptions of a new web-based virtual navigator

**Number of articles included in qualitative synthesis (n = 16)**
- representing 14 separate research studies
studies included stage I–III melanoma and one study included stage III melanoma. In two studies, the stage of melanoma was unknown. One study looked at intrafamily risk communication, one study included views on a general practitioner-led follow-up clinic and one study looked at patient satisfaction with follow-up care.

The overall quality of the studies was good (Table 4); however, only two studies located the research culturally or theoretically and only one 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 5 for a summary of the metasynthesis and Table 2 for a full version. Key concepts within their constituent categories are illustrated using representative textual excerpts from selected findings (Table 6). The synthesized 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.

Synthesized 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 that 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 the 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 shock 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.

Table 1 Search strategy for Medline on Ovid

|   |   |
|---|---|
| 1 | (melanoma adj1 skin).mp. [mp=title, abstract, original title, name of substance word, subject 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, 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, 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 |
Table 2 Metasynthesis of the needs and experiences of patients with skin cancer

| Findings                                                                 | Categories | Synthesized findings                                                                 |
|--------------------------------------------------------------------------|------------|---------------------------------------------------------------------------------------|
| When the diagnosis of cancer is confirmed it frequently induces significant emotional distress for the patient | Shock      | Synthesized 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 |
| Reaction to diagnosis (C)                                               |            |                                                                      |
| Reaction to the diagnosis (C)                                            |            |                                                                      |
| Diagnosis – impacts (C)                                                  |            |                                                                      |
| Reaction to diagnosis-shock (C)                                          |            |                                                                      |
| Personality and feelings (C)                                             |            |                                                                      |
| Uncertainty (C)                                                          | Fear and distress |                                                                      |
| Causal attributions (U)                                                  |            |                                                                      |
| Waiting to receive results – a stressful experience (U)                  |            |                                                                      |
| Need for inclusion of psychological support during reviews (C)           |            |                                                                      |
| Feeling (mis)understood (C)                                              |            |                                                                      |
| Views on supportive care and areas of unmet need (U)                     |            |                                                                      |
| Perceived lack of adequate follow-up care and support (U)                |            |                                                                      |
| Appearance and information needs (U)                                    |            |                                                                      |
| Access to the right amount and type of cancer information (U)            |            |                                                                      |
| Preference for early introduction (U)                                    |            |                                                                      |
| Information about my melanoma... (C)                                    |            |                                                                      |
| Clarity of information (U)                                               |            |                                                                      |
| Quality of information (C)                                               |            |                                                                      |
| Information at the right time (C)                                        |            |                                                                      |
| Receiving helpful information (C)                                       |            |                                                                      |
| Difficulties in accessing treatment (U)                                  |            |                                                                      |
| Some survivors experienced anxiety if outdoors without sun protection (U)|            |                                                                      |
| Ongoing fear about the possibility of metastases (U)                     |            |                                                                      |
| Skills and resources used to try to cope with melanoma risk (U)         |            |                                                                      |
| Anger and frustration (U)                                                |            |                                                                      |
| Anxiety and fear (C)                                                     |            |                                                                      |
| Depression (U)                                                           |            |                                                                      |
| Cancer-related stress (U)                                               |            |                                                                      |
| Functional effects (U)                                                  |            |                                                                      |
| Requiring a more complex surgery (C)                                    |            |                                                                      |
| Ongoing effects after surgery (C)                                        |            |                                                                      |
| Pain and physical limitation (U)                                         |            |                                                                      |
| Ongoing physical problems (U)                                            |            |                                                                      |
| Open sores that failed to heal (U)                                       |            |                                                                      |
| Itching localized to the lesion (U)                                      |            |                                                                      |
| Daily activities (U)                                                     |            |                                                                      |
| Cosmetic and functional impact (U)                                       |            |                                                                      |
| Altered body image (U)                                                  |            |                                                                      |
| Self-concept and perceptions of physical disfigurement after melanoma treatment (C) |            |                                                                      |
| Disfigurement (U)                                                       |            |                                                                      |
| Emotional well-being (U)                                                |            |                                                                      |
| Receiving a melanoma diagnosis served to either strengthen or place stress on survivors’ relationships with romantic partners (U) |            |                                                                      |
| Diagnosis prompted younger female survivors to shift their attitudes towards childbearing (U) |            |                                                                      |
| Effects on working relationships (U)                                     |            |                                                                      |
| Effects on family relationships (U)                                      |            |                                                                      |
| Disruption on daily life activities (U)                                  |            |                                                                      |
| Social impact (U)                                                        |            |                                                                      |

(continued)
| Findings                                                                 | Categories                                           | Synthesized findings                          |
|-------------------------------------------------------------------------|------------------------------------------------------|-----------------------------------------------|
| Melanoma diagnosis elevated the importance of retaining healthcare insurance and purchasing life insurance for younger survivors (U) | Financial concerns and consequences                  |                                               |
| Economic concerns were far more prominent for younger melanoma survivors; financial concerns were not a major worry for older survivors, with insurance Medicare coverage (C) |                                                      |                                               |
| Increased financial costs (U)                                           |                                                      |                                               |
| Consequences of improved cancer knowledge (U)                          |                                                      |                                               |
| Receiving good news from physician screenings was psychologically reassuring for survivors (U) |                                                      |                                               |
| Melanoma diagnosis prompted many survivors to assess and reprioritize life values and develop a more positive life outlook (U) |                                                      |                                               |
| Some survivors minimized their melanoma diagnosis, regarding melanoma to be a disease that develops on the surface of the skin (U) |                                                      |                                               |
| Perceptions of cancer status and likelihood of future recurrences varied (C) |                                                      |                                               |
| Living and coping beyond nodal relapse (U)                              |                                                      |                                               |
| Coping with nodal relapse (U)                                           |                                                      |                                               |
| Trivialization-attempts to rationalize the diagnosis with the good prognosis (C) |                                                      |                                               |
| Adaptation to the disease – minimizing the experience (C)               |                                                      |                                               |
| MM – Adaptation to the disease – changing behaviours (C)                |                                                      |                                               |
| MM Coping – information seeking-religious faith (C)                     |                                                      |                                               |
| MM – Making sense of the disease – social comparison-causal attribution (C) |                                                      |                                               |
| Controllability (C)                                                    |                                                      |                                               |
| Diagnosis – coping strategies (C)                                       |                                                      |                                               |
| Treatment – coping strategies (U)                                       |                                                      |                                               |
| Extended survivorship – coping strategies (C)                          |                                                      |                                               |
| Professional support helped in coping (C)                               |                                                      |                                               |
| Support from family and friends helped in coping (U)                    |                                                      |                                               |
| Thinking strategies helped in coping (U)                                |                                                      |                                               |
| Concealing distress and ‘putting on a brave face’ around others (U)     |                                                      |                                               |
| Redirecting attention away from the disease (C)                        |                                                      |                                               |
| Religious beliefs and practices helped in coping (U)                    |                                                      |                                               |
| Feeling relieved and reassured (C)                                      |                                                      |                                               |
| Reaction to clinical diagnosis (C)                                      |                                                      |                                               |
| Recurrence and new lesions (U)                                          |                                                      |                                               |
| What to do if I’m worried between GP follow-up appointments . . . (C)   |                                                      |                                               |
| Negative associations with seeing dermatologists were a discomfort and embarrassment being naked and anxiety prior to appointments that the dermatologist may identify a suspicious area (U) |                                                      |                                               |
| Uncertainty (U)                                                        |                                                      |                                               |
| Fear of the sun (U)                                                    |                                                      |                                               |
| Fear (U)                                                                |                                                      |                                               |
| Persistent uncertainty (U)                                              |                                                      |                                               |
| Threat perceived as pervasive (C)                                      |                                                      |                                               |
| Perceptions of melanoma risk and personal susceptibility (U)           |                                                      |                                               |
| Fear of recurrence (U)                                                 |                                                      |                                               |
|                                                                           |                                                      |                                               |
| Synthesized 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, characterized 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 |                                                      |                                               |

(continued)
Table 2 (continued)

| Findings | Categories | Synthesized findings |
|----------|------------|----------------------|
| Increased awareness (U) | Self-monitoring |
| Information needs about checking skin (U) | |
| Not sure what to look for (U) | |
| Participating in my follow-up (U) | |
| ‘A passing interest’- not much talk about risk (U) | |
| ‘I trust them to give me knowledge’– wanting accurate and understandable melanoma information (C) | |
| Patient perceptions of information received at the HRC (C) | |
| Examining myself... (U) | |
| Receiving melanoma diagnosis elevated the importance of being more vigilant and proactive regarding monitoring one’s health and interacting with physicians to obtain good care (U) | |
| Survivors became more conscious of sun exposure and expanded use of sun-protection measures following diagnosis (U) | |
| Melanoma survivors sought to continue outdoor pursuits but used sun protection (U) | |
| A majority of survivors were more likely to engage in regular, consistent sun protection during the summer months (U) | |
| The perception that melanoma is not a serious cancer and confidence that dermatologists will identify new melanomas at an early stage both minimized the necessity of establishing consistent sun protection habits for some survivors (U) | |
| Survivors regularly visited dermatologists for screening and that seeing a dermatologist is an effective strategy to ensure new melanomas would be identified early (U) | |
| Skin self-examination varied significantly across the sample but most did not conduct skin self-examinations on a regular basis (C) | |
| Lack of confidence in ability to identify a suspicious mole was cited as a barrier to conducting skin self-examination, and some survivors preferred to offload the responsibility to the doctor (U) | |
| Fear of the sun (U) | |
| Behavioural responses to threat (U) | |
| Low confidence in one’s ability to detect melanoma (i.e. self-efficacy) (U) | |
| An appropriate time for questions (C) | |
| Needing to know, not needing to know – ambivalence about information needs (U) | |
| Changes in behaviour (U) | |
| Spreading the word (C) | Understanding and communicating risk |
| Awareness and understanding of risk (U) | |
| Families facilitate and hinder communication (U) | |
| Promoting melanoma prevention and detection in the family (C) | |
| An obligation to tell others (U) | |
| Survivors were aware their diagnosis increased melanoma risk (genetic susceptibility) and the need for family members to be screened, yet many did not discuss risk reduction with family members (U) | |

(continued)
Table 2 (continued)

| Findings                                                                 | Categories                  | Synthesized findings                                                                                   |
|-------------------------------------------------------------------------|-----------------------------|--------------------------------------------------------------------------------------------------------|
| Making sense of the disease (C)                                          |                              | Synthesized 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 organization of service provision. Healthcare professionals can assist patients during treatment and beyond through clear and open communication, a caring approach and by providing support for positive coping strategies |
| Barriers to accessing emotional support (C)                              |                              |                                                                                                         |
| Beliefs about the causes of melanoma and how these relate to personal risk (U) |                              |                                                                                                         |
| Potential problems of using technology to follow-up my melanoma (U)      |                              |                                                                                                         |
| How personal characteristics influence my orientation towards technology in my melanoma follow-up (U) |                              |                                                                                                         |
| 'The healthcare system gets in the way'- system-based constraints on communication (U) |                              |                                                                                                         |
| Comprehensive (U)                                                        |                              |                                                                                                         |
| A complement to information received from healthcare providers (U)       |                              |                                                                                                         |
| Accessible 24–7 (C)                                                      |                              |                                                                                                         |
| Ability to partition cancer information into manageable chunks (U)       |                              |                                                                                                         |
| Patient perceptions of areas for improvement in clinical care (C)        |                              |                                                                                                         |
| Patient perceptions of areas for improvement in clinical care (C)        |                              |                                                                                                         |
| Why GP-led follow-up a good thing for me… (U)                           |                              |                                                                                                         |
| What’s worse about hospital follow-up is… (U)                           |                              |                                                                                                         |
| Preferring a more joined up approach between specialists (C)            |                              |                                                                                                         |
| Treatment satisfaction (U)                                               |                              |                                                                                                         |
| Satisfaction (C)                                                        |                              |                                                                                                         |
| Which technologies for my melanoma follow-up (U)                        |                              |                                                                                                         |
| Value added by using technology for my melanoma follow-up (U)           |                              |                                                                                                         |
| 'Is it cancer’– desiring competent and caring communication (U)          |                              |                                                                                                         |
| Patient perceptions of clinical care received at the HRC (C)             |                              |                                                                                                         |
| Satisfaction with clinical care among high-risk patients with melanoma (U) |                              |                                                                                                         |
| Patient perceptions of emotional care received at the HRC (C)            |                              |                                                                                                         |
| My GP follow-up appointments… (C)                                       |                              |                                                                                                         |
| What I prefer about GP follow-up compared with the hospital… (U)        |                              |                                                                                                         |
| Some things I’m not so sure about with GP follow-up… (C)                |                              |                                                                                                         |
| What’s better about hospital follow-up is… (U)                         |                              |                                                                                                         |
| When you directly comparing the two types of follow-up… (U)             |                              |                                                                                                         |
| Influence of personal characteristics (C)                               |                              |                                                                                                         |
| Discordant views (C)                                                     |                              |                                                                                                         |
| Survivors believed it is important to find a dermatologist whom they perceive to be competent – some survivors had dermatologists who had missed their melanoma (C) |                              |                                                                                                         |
| Time spent with healthcare professionals (C)                            |                              |                                                                                                         |
| Receiving more follow-up postnodal relapse (C)                          |                              |                                                                                                         |
| Valuing positive messages (U)                                            |                              |                                                                                                         |
| Satisfaction with care – causal attributions (C)                        |                              |                                                                                                         |
| MM treatment – satisfaction with care (C)                               |                              |                                                                                                         |
| Specialized medical care (U)                                            |                              |                                                                                                         |
| Difficulties in accessing treatment (U)                                  |                              |                                                                                                         |

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

Synthesized finding 2: the time around treatment and immediately afterwards

For the time around treatment and immediately afterwards, the experience of having skin cancer varies depending upon the type, stage and treatment. A skin cancer diagnosis can have a significant emotional, physical, social and financial impact, some of which can be long-lasting, and patients and their families may need support in these areas. 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 whether things would get back to how they 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 ... 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, nonadvanced 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. p34–5, M)

In some cases, patients with skin cancer 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, nonadvanced 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 healthcare and life insurance was important for young melanoma survivors in U.S. 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. p111, M stages I–III)

Patients developed a range of mechanisms to cope with their cancer, including avoidance, positive reframing, 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 study focused particularly on patients who had transitioned from an initial diagnosis of melanoma to nodal relapse. These patients used coping skills learned from their initial diagnosis to help with a diagnosis of nodal relapse.
Table 3  Characteristics of included studies

| Study and setting | Methods | Participants | Data analysis | Phenomenon of interest |
|-------------------|---------|--------------|---------------|------------------------|
| Bath-Hextall (2013). 21 U.K. | Mixed methods study | 77 Participants (BCC and SCC) attending a skin cancer clinic and with a new clinical diagnosis of NMSC. 15 participants were interviewed | Thematic analysis | The needs, experiences and knowledge of individuals with NMSC from diagnosis up to 1 year |
| Loescher (2009). 30 U.S.A. (Two papers) | In-depth interviews separately for patients with melanoma and for family members | 11 participants with newly diagnosed melanoma and with a family history of melanoma recruited from the Cutaneous Oncology Program 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). 33 Australia (Two papers) | Semistructured telephone interviews of participants who were at the follow-up stage | 20 high-risk participants with melanoma (nine men, 11 women) recruited via the clinical database of the High Risk Clinic (HRC) and who had attended a minimum of three clinical consultations at the HRC. High risk is defined as multiple diagnoses of primary invasive melanoma, or diagnosis of one primary invasive melanoma in addition to dysplastic naevus 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). 23 U.K. (Scotland). | Semistructured telephone interviews | 18 participants with melanoma 10 men and eight women 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). 31 U.S.A. | Eight focus groups | Follow-up (1–10 years) of 48 melanoma survivors (18 men, 30 women) attending the Memorial Sloan–Kettering Cancer Center 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 |

(continued)
| Study and setting          | Methods                                      | Participants                                                                 | Data analysis     | Phenomenon of interest                                                                 |
|---------------------------|----------------------------------------------|-------------------------------------------------------------------------------|-------------------|---------------------------------------------------------------------------------------|
| Stamataki (2015)           | Semistructured interviews in a location convenient to the participants, at the study hospital or in the patient’s home | 15 participants (eight women, seven men) with melanoma stages I–III and between 3 months to 5 years post-diagnosis. Recruited from a 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)            | Semistructured interviews conducted in a quiet room when they were attending for outpatient review appointments | Six participants with melanoma (two men, four women) 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 2 years. Recruited from a consultant plastic surgeon’s 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)              | Semistructured interviews                    | 10 men presenting to the dermatology department having been referred by GP for suspected melanoma | Content analysis  | Men’s perception of malignant melanoma                                                  |
| Winterbottom (2004)        | Semistructured interviews conducted in a consulting room at the dermatology centre | 16 participants at different stages in the disease trajectory (five malignant melanoma, four SCC and seven BCC), recruited from a dermatology clinic. Mean age 63.8 years (range 34–90) Interviews took place 3–48 months after diagnosis (mean 8 months and 1 week) | Thematic content analysis | Experience of diagnosis and treatment of skin cancer                                    |
| Tan (2014)                 | Semistructured interviews                    | 19 participants diagnosed with stage III melanoma and free of disease recurrence at their most recent follow-up (10 women, nine men) attending Melanoma Institute of Australia, a multidisciplinary melanoma research and treatment centre. Mean age 58 years, SD 14 (range 30–82) | Thematic analysis | Psychosocial impacts experienced by patients with stage III melanoma (and their caregivers) throughout the course of the disease, and the coping responses they utilized in an attempt to promote psychosocial adjustment |
| Moore (1996)               | Semistructured in-depth interviews           | Seven patients with melanoma (three men and four 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)              | Semistructured interviews during treatment and follow-up | 11 patients with melanoma (six men and five women) receiving treatment at a large teaching hospital in the U.K. 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)            | Cross-sectional study using semistructured telephone interviews | 34 patient interviews were conducted on newly diagnosed or recurrent patients with BCC. Group 1 comprised 11 patients with superficial subtype BCC and two patients with nodular subtype BCC. Group 2 comprised 12 patients | Content analysis  | Symptoms, impact of symptoms and the health-related quality of life (HRQoL) impact of BCC on the daily lives of patients across different stages of the disease |
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)

Both patients with keratinocyte carcinoma and patients with melanoma 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 regarding risks of recurrence and how and when 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. (McLoone 2013. p1106, M)

### Synthesized finding 3: the time after treatment and the follow-up period

Skin cancer survivors and their families may have ongoing needs relating to support, information and risk management. The survivorship phase can be a period of liminality characterized by fear and uncertainty, related to the possible, yet uncertain, risk of skin cancer recurrence. Patient care and information needs during skin cancer survivorship include the ability to identify, prevent and manage further risk for themselves and their family. However, many patients reported a lack of information.

### Table 3 (continued)

| Study and setting | Methods | Participants | Data analysis | Phenomenon of interest |
|-------------------|---------|--------------|--------------|-------------------------|
| Hall (2014)²⁹     | Semistructured interviews were conducted, either face-to-face or on the telephone | 21 participants (37–83) receiving structured follow-up for melanoma | Thematic analysis | To compare descriptively the experiences, symptoms and HRQoL impact of patients with nonadvanced BCC with those of patients with locally advanced or metastatic disease |
| U.K. (Scotland)   |         |              |              |                         |

BCC, basal cell carcinoma; SCC, squamous cell carcinoma; NMSC, nonmelanoma skin cancer.

### Table 4

| Studies                      | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Dep |
|------------------------------|----|----|----|----|----|----|----|----|----|-----|-----|
| Bath-Hextall (2013)²¹        | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Hall (2014)²⁹                | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| McLoone (2013)¹¹             | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Loescher (2009)¹⁰            | Y  | Y  | Y  | Y  | N  | N  | N  | Y  | Y  | Y   | ↓   |
| Murchie (2010)²³             | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Oliveria (2013)¹¹            | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Stamatakis (2015)²⁸          | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Stothers (2015)²⁵            | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ←   |
| Taylor (2009)²⁴              | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Winterbottom (2004)²²        | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| McLoone (2012)²⁴             | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Tan (2014)²⁵                 | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Moore (1996)²⁶               | U  | Y  | Y  | Y  | Y  | Y  | Y  | Y  | Y  | Y   | ←   |
| Clarke (2006)²⁷              | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |
| Steenrod (2015)²¹            | U  | Y  | Y  | Y  | Y  | N  | N  | Y  | Y  | Y   | ↓   |

Y, yes; N, no; U, unclear; Dep, dependability grade. Q2, Q3, Q4, Q6 and Q7 are questions for judging dependability. Horizontal arrow indicates that the findings remain unchanged. Down arrow indicates that the findings were downgraded one level of dependability.
The risk of me having another occurrence of melanoma is probably greater ... and that is frightening. (McLoone 2013. p1997, M)

Many patients reported engaging more proactively in risk minimization by using sun-avoidance measures and undertaking regular skin self-examination. Some patients felt that 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)

Table 5 Synthesized findings and categories. A synopsis

| Synthesized finding                                                                 | Categories                                                                 |
|------------------------------------------------------------------------------------|---------------------------------------------------------------------------|
| Synthesized finding 1: the time of diagnosis                                       | • Shock                                                                  |
| Diagnosis is a time of shock and distress, where patients have significant support  | • Fear and distress                                                      |
| and information needs, irrespective of the type of skin cancer. For many patients, | • Needing emotional support                                               |
| this diagnosis can come as a severe shock, especially for those who believe their  | • Needing information and clear communication                             |
| symptoms are relatively mild and therefore nothing to worry about                  |                                                                           |
| Synthesized finding 2: the time around treatment and immediately afterwards        | • An emotional journey                                                   |
| For the time around treatment and afterwards, the experience of having skin cancer | • Physical consequences                                                  |
| varies depending upon the type, stage and treatment. The impact of a skin cancer    | • Changes to body image                                                  |
| diagnosis can have a significant emotional, physical, social and financial impact, | • Social and relational changes and impacts                              |
| some of which can be long-lasting, and for which patients and their families may   | • Financial concerns and consequences                                     |
| need support. Patients cope with their experiences in a variety of ways              | • Coping                                                                 |
| Synthesized finding 3: the time after treatment and the follow-up period           | • Being in limbo: ongoing fear and uncertainty                           |
| Skin cancer survivors and their families may have ongoing support, information and | • Self-monitoring                                                        |
| risk-management needs. The survivorship phase can be a period of liminality,       | • Understanding and communicating risk                                    |
| characterized 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 their family                                  |                                                                       |
| Synthesized finding 4: satisfaction with skin cancer care and confidence in        | • Structure and follow-up services                                       |
| healthcare providers                                                               | • Competence, clinical knowledge and compassion                           |
| Satisfaction with skin cancer care is influenced by the perceived competence of the |                                                                       |
| relevant healthcare providers and by the structure and organization of service     |                                                                       |
| provision. Healthcare professionals can assist patients during treatment and beyond |                                                                       |
| through the use of clear and open communication, a caring approach and by          |                                                                       |
| providing support for positive coping strategies                                   |                                                                       |

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 cancer, is I am much more aware of being in the sun without some sort of protection. (Steenrod 2015. p194, nonadvanced 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)
### Table 6 Categories and representative quotes. A synopsis

| Categories                              | Representative quotes                                                                                                                                                                                                 |
|----------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Shock                                  | 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 shock of my own and switched off I think. (Moore 1996. p60, M)  |
|                                        | 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 1–2 cm) 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) |
|                                        | …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)                                                                                                                                 |
|                                        | 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) |
|                                        | …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) |
|                                        | 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)                                                                                                                                 |
|                                        | 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)                                                                                                                        |
|                                        | 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)                                                                                                                                 |
| Fear and distress                       | 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)  |
|                                        | 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 6 months’ time. (Moore 1996. p62, M)                                                                                                                                 |
| Needing emotional support               | 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, nonadvanced BCC)  |
| (Emotional needs at diagnosis)          | …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 (Stamatakis 2015, M stage IIIC)  |
|                                        | There’s 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)  |
| Needing information and clear communication | 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. p35, Melanoma relapse) |
|                                        | Maybe a little bit more information about what the scar would feel like and look like… (Bath-Hextall et al. 2013. p7, BCC)                                                                                                                                 |
|                                        | …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? (Stamatakis 2015. p785, M stage IIC)  |
|                                        | 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? (Stamatakis 2015. p785, M)  |
### Table 6 (continued)

| Categories                  | Representative quotes                                                                                                                                                                                                 |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| An emotional journey        | 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. p.12, M)                                                                                      |
|                             | Nobody rings me up and says ‘How are you going?’; ‘Are you feeling allright?’ I suppose they’ve got so many they can’t remember everybody. (Tan 2014. p.15, M stage III)                                                                 |
|                             | I had no idea how to put (the stocking) on. I had no understanding of lymphoedema. (Tan 2014. p.12, stage III M)                                                                                                                                                                                        |
|                             | Oh look, I couldn’t care less about scarring. I would rather a scar than, you know, be dead. (McLoone 2012. p.1106, M)                                                                                                                                            |
|                             | 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. p.111, M) |
|                             | I’d tend to find the sadness in everything... I did have a few times 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. p.17, M stage III) |
|                             | 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. pp.16–17, M stage III) |
|                             | 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. p.193, nonadvanced BCC) |
|                             | 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)                                                                 |
|                             | Uh, I’m tired of having my body cut. I mean, you could say it’s at times mildly depressing. (Steenrod 2015. p.194, nonadvanced BCC)                                                                                                                                              |
| Physical consequences       | ...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. p.34–35, M) |
|                             | 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 traumatizing. (Tan 2014. pp.12–13, M stage III) |
|                             | 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. pp.14–15, M stage III) |
|                             | 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. p.194, locally advanced and/or metastatic BCC) |
|                             | 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. p.193, locally advanced and/or metastatic BCC) |
|                             | 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. p.193, nonadvanced BCC) |
| Changes to body image       | 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. p.17, M stage III)                                                                 |
|                             | 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 congranulating 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. (Stamatakis 2015. p.783, M) |
### Table 6 (continued)

| Categories | Representative quotes |
|------------|------------------------|
| **Financial concerns and consequences** | 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) Oh look, I couldn’t care less about scarring. I would rather a scar than, you know, be dead. (McLoone 2012. p1108, M) 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) 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) Well, I wear a hat and the wig because after all these surgeries I have no hair, it’s all scar tissue and (sigh) I think my mind has shut down. (Steenrod 2015. p194, nonadvanced BCC) 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 steal 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) It’s (hearing about increase likelihood of getting a new melanoma if you get pregnant) a disappointment. He (the 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 vs. taking care of your own body. I’m 39 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) ...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) It puts a black cloud above (your life)... my husband’s family is organizing 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) 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, nonadvanced BCC) What it did do, I think, more than anything else, was to make me understand the effects, of the impact it would have on other people in more serious cases (Winterbottom 2004. p231, M) I don’t know if it’s leisure, but it’s basically all the yard work. Back when they were open sores it would stop (me from) meeting people—it would stop (me from) meeting people—talking to people and basically staying in. (Steenrod 2015. p194 locally advanced and/or metastatic BCC) In terms of my life, I think it just made me focus down on the day to day and not be so overwhelmed 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) 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. p111, M stages I–III) 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–III) I wouldn’t want to go in another trial because I’d have to be in Sydney every 3 weeks and it’s going to cost us AUS$600 every time we went... and we just haven’t got that money. (Tan 2014. p13, M stage III) |
| **Social and relational changes and impacts** | 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) Oh look, I couldn’t care less about scarring. I would rather a scar than, you know, be dead. (McLoone 2012. p1108, M) 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) 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) Well, I wear a hat and the wig because after all these surgeries I have no hair, it’s all scar tissue and (sigh) I think my mind has shut down. (Steenrod 2015. p194, nonadvanced BCC) 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 steal 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) It’s (hearing about increase likelihood of getting a new melanoma if you get pregnant) a disappointment. He (the 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 vs. taking care of your own body. I’m 39 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) ...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) It puts a black cloud above (your life)... my husband’s family is organizing 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) 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, nonadvanced BCC) What it did do, I think, more than anything else, was to make me understand the effects, of the impact it would have on other people in more serious cases (Winterbottom 2004. p231, M) I don’t know if it’s leisure, but it’s basically all the yard work. 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) In terms of my life, I think it just made me focus down on the day to day and not be so overwhelmed 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) 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. p111, M stages I–III) 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–III) I wouldn’t want to go in another trial because I’d have to be in Sydney every 3 weeks and it’s going to cost us AUS$600 every time we went... and we just haven’t got that money. (Tan 2014. p13, M stage III) |
### Table 6 (continued)

| Categories                          | Representative quotes                                                                                                                                 |
|-------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| **Coping**                          | 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. pp35–6, M with nodal relapse) |
|                                    | I know it’s not severe at all if you have it removed quickly. (McLoone 2012. p1106, M)                                                                                                                       |
|                                    | …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)                                                                        |
|                                    | 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) |
|                                    | 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. p17, M stage I–III) |
|                                    | 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) |
|                                    | 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–III) |
|                                    | 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 6 months. (Tan 2014. pp18–19, M stage I–III) |
|                                    | 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. pp20, M stage I–III) |
| **Being in limbo (ongoing fear and uncertainty)** | 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) |
|                                    | 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) |
|                                    | 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) |
|                                    | The risk of me having another occurrence of melanoma is probably greater… and that is frightening. (McLoone 2013. p1997, M)                                                                                  |
|                                    | It’s weird ‘cos 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 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, ‘cos 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 (Stamatakis 2015. p782, M) |
|                                    | 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 (McLoone 2013. p1106, M) |
|                                    | 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. (McLoone 2012. p1106, M) |
| **Self-monitoring**                | 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) |
|                                    | 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) |

(continued)
Table 6 (continued)

| Categories                      | Representative quotes                                                                                                                                                                                                 |
|---------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Understanding and communicating risk | 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) 
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) 
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. I wasn’t sure what it meant. (Loescher 2009. p303, M) 
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). (McLoone 2013. p1197, 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, nonadvanced BCC) 
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) 
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) 
No, no I just leave that to the experts. (Hall 2014. p1666, M) 
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) 
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 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? (Moore 1996. p67, M) 
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) 
…it has raised awareness significantly in our family now, yeah. I’ve been into town today and bought a moisturizer with SPF25 or something or other, so yeah. So I’ll wear that which constantly now rather than general moisturizers. (Bath-Hextall 2013. p7, BCC) 
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) 
...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) 
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. (McLoone 2012. p1107, M) 
‘At (hospital) 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 1970s.’ (Murchie 2010. p230, M) 
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) 20 minutes late, I could be late and I told them... if I get a parking fine, I’m passing it onto you. (McLoone 2013. p1998, M) 
...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) 
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) 
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) 
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) 

Structure and follow-up services

Competence, clinical knowledge and compassion

(continued)
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 organization of service provision. Healthcare 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 patients with melanoma 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 (hospital) it was bell-lam, 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 1970s. (Murchie 2010. p230, M)

Patients were satisfied with providers whom they perceived to be clinically knowledgeable and who treated them in a holistic manner with compassion and empathy. In cases where either one of these facets was missing, care was perceived to be 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 go, you really had five melanomas’. I don’t want that anymore. (Loescher 2009. p304, M)

Patients with melanoma in a general practitioner (GP)-led follow-up study had less confidence in the GP compared with 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 compared with the hospital appointments.

Synthesized 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 organization of service provision. Healthcare professionals can assist patients during treatment and beyond through clear and open communication, a caring approach and by providing support for positive coping strategies.

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 among 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: ‘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)

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)

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)

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)

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’. (Stamatakis 2015. p786, M)

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 2013. p35, M nodal relapse).

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)

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)
Table 7 ConQual summary of findings

| Synthesized findings                                                                 | Dependability rating | Credibility rating | ConQual rating | Comment                                                                 | Comment                                                                 |
|--------------------------------------------------------------------------------------|----------------------|-------------------|----------------|------------------------------------------------------------------------|------------------------------------------------------------------------|
| Diagnosis is a time of shock and distress when patients have significant support and information needs | ↓                    | ↓                 | Moderate       | The overall methodological quality was good, although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings. | The overall methodological quality was 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 on the type, stage and treatment. The impact of a skin cancer diagnosis can have a 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 | ↓                    | ↓                 | Moderate       | The overall methodological quality was good, although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings. | The overall methodological quality was 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 | ↓                    | ↓                 | Moderate       | The overall methodological quality was good, although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings. | The overall methodological quality was 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 structure of service provision. Healthcare professionals can assist patients during treatment and beyond through clear and open communication, a caring approach and by providing support for positive coping strategies | ↓                    | ↓                 | Moderate       | The overall methodological quality was good, although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings. | The overall methodological quality was good, although there was general poor reflexivity. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings. |
Discussion

The previous systematic review in 2010 highlighted the need for further research into the needs and experiences of patients with skin cancer. Six years later, a further 12 studies have been published; however, only two of these studies exclusively considered keratinocyte carcinoma. Despite the high incidence rates of keratinocyte carcinoma worldwide, 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 skin cancer; however, there are still very few studies that focus on the most common cancer in humans (keratinocyte carcinoma) and therefore this is an area for further research.

At diagnosis, despite the fact that keratinocyte carcinomas and melanomas can have very different prognoses, healthcare 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.

The time around treatment and immediately afterwards can be very different for patients with skin cancer depending on 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 also 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 support needs of people with cancer. Our findings are also consistent with other studies regarding other cancer types.

Patients require clear supportive information about surveillance and risk management and this should include information regarding how to identify skin changes, prevent and manage further risk – not just for themselves but also for their family. Knowledge about recognizing signs of skin cancer is particularly important as 44% of patients with a keratinocyte carcinoma will develop additional lesions within 3 years and there is a 2.8% risk of developing a second melanoma after 5 years and a 3.6% risk after 10 years. Other quantitative studies have also shown that patients with keratinocyte carcinoma experience anxiety and worry about future skin cancers, and have unmet needs regarding the health system and information-related matters.

The overall methodological quality of the included studies was good, although there was general poor reflexivity. Providing an overall score for the level of confidence in qualitative review findings is a relatively new development, 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, an element of subjectivity will always remain when assigning a level of credibility. The included findings were mainly unequivocal, with fewer equivocal and no unsupported findings. Therefore, the overall dependability and credibility of all synthesized findings were downgraded by one level and the overall ConQual score was medium (Table 7).

The review included 14 studies representing only four countries; therefore, care must be taken in generalizing the results of this review to other countries. In particular, the category ‘financial concerns and consequences’ applies only to the U.S.A. and other countries with similar health systems.

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

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 on the type of cancer and its severity. Crucially, this 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 is often accompanied by fear and uncertainty around the identification of new skin abnormalities.

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