




Needs and preferences of patients regarding basal cell carcinoma and cutaneous squamous cell carcinoma care: a qualitative focus group study*

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Summary

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Background Despite the high and rising incidence rate of keratinocyte cancer (KC) and the importance of incorporating patient values into evidence-based care, few studies have focused on the perspectives of patients with KC.

Objectives To identify the needs and preferences of patients with basal cell carcinoma (BCC) and squamous cell carcinoma (SCC) regarding care.

Methods A qualitative study was conducted consisting of three focus groups with patients with BCC and three focus groups with patients with SCC. In total 42 patients participated. In each focus group, the patients' needs and preferences regarding treatment and follow-up were discussed, using a predefined topic list. All sessions were transcribed verbatim and analysed by two researchers.

Results The following needs and preferences were identified: (i) the need to receive all relevant, tailored information; (ii) a physician who takes you seriously and communicates well; (iii) a short waiting period and the best treatment with direct results; (iv) to be seen by the same physician; a preference for a dermatologist during (v) treatment and (vi) follow-up; (vii) a general need for structured follow-up care and (viii) a full-body skin examination during follow-up. Patients with BCC additionally expressed the need for openness and transparency and wanting to participate in shared decision making.

Conclusions It is advocated to organize skin cancer care that is better tailored to the needs of patients with KC, providing patient-centred care. This should include investing in the patient–physician relationship, and personalizing the type and form of information and the follow-up schedules. Adding the patient's perspective to current guidelines could facilitate this process.

What's already known about this topic?

- The incidence of skin cancer is high and increasing, which poses a considerable burden on healthcare systems.
- Patient values are a core component of evidence-based care, yet studies focusing on patients' needs and preferences regarding care for basal cell carcinoma (BCC) and squamous cell carcinoma (SCC) are scarce.

What does this study add?

- This qualitative study provides an in-depth understanding of the preferences of patients with keratinocyte cancer and needs regarding care.

- Patients with BCC and SCC emphasized the importance of receiving all relevant information tailored to their specific situation.
- Patients with BCC additionally expressed the need to participate in shared decision making, whereas patients with SCC stated that they do not want to be involved.
- Whereas both patient groups prefer periodic follow-up visits, some patients with BCC indicated not needing this if they have quick access to a dermatologist whenever they detect new lesions.

What are the clinical implications of this work?

- In order to tailor care to the needs and preferences of patients with BCC and SCC, it is advocated to provide patient-centred care.
- This should involve investing in the patient–physician relationship and personalizing the type and form of information, the methods of explanation and the follow-up schedules.
- The patients' perspectives found in this study may be incorporated into BCC and SCC guidelines in order to improve quality of care.

Basal cell carcinoma (BCC) and squamous cell carcinoma (SCC) are among the most common cancers, with increasing incidences worldwide.^{1,2} Due to their keratinocytic origin they are nowadays commonly referred to as keratinocyte carcinoma (KC).³ The estimated global prevalence of KC was 5 529 600 in 2013.⁴ Although the costs per case are low, this high prevalence drives the costs of KC up to €600 million, €350 million, €150 million and €100 million in the U.S.A., Australia, Germany and the U.K., respectively.⁵ KC therefore poses a considerable burden on healthcare systems.

To manage finite sources wisely, a strong initiative has spread over all medical societies over the past 5 years, which aims to reduce low-value care^{6–10} (i.e. healthcare that is of little or no value to the patient and consequently should not be provided routinely, or at all).¹¹ Providing follow-up care to patients with low-risk BCC has been defined as an example of low-value care. Although the risk of a subsequent BCC is high (29% in 5 years),¹ evidence is lacking that regular follow-up visits translate into improved patient outcomes.¹² In addition, another trend aimed to reduce costs has been care substitution, which aims to shift skin cancer care from medical specialists towards general practitioners (GPs), or nurse practitioners (NPs) and physician assistants (PAs) specialized in dermatology.^{13–15} It is of paramount importance that these GPs, NPs and PAs have had sufficient dermatological training.

Evidence-based medicine includes three components: research-based evidence, professional expertise and patient values.¹⁶ Given that patient values are a core component of evidence-based medicine,¹⁶ it is surprising that the experiences, needs and preferences of patients with KC have received limited attention and were focused mainly on patients with melanoma.^{17–34} A recently conducted qualitative review³⁵ on the needs and experiences of patients with skin cancer found that only three of 16 studies included patients with KC.^{29,36,37} These qualitative KC studies focused mainly on experiences,

the psychological impact of hearing the diagnosis, and quality of life, and all identified the need for information among patients. However, an in-depth evaluation of preferences and needs regarding treatment and follow-up care is lacking for this large patient group.³⁵

The aim of the current qualitative study was therefore to identify the needs and preferences of patients with BCC and SCC regarding KC care. The results of this study can be used as input to organize skin cancer care that is better tailored to the needs of patients and incorporates patient values and preferences in addition to evidence and clinical expertise.

Patients and methods

Study design and methodological considerations

A qualitative study consisting of six focus groups was conducted. Qualitative research is ideally suited to provide an in-depth picture of patients' needs and preferences.^{38,39} Furthermore, the interactive component of the focus groups enables people to ponder, reflect and listen to the experiences and opinions of others. This interaction helps participants compare their own personal realities with those of others.⁴⁰

This focus group study was designed and is reported in accordance with the SRQR (Standards for Reporting Qualitative Research) recommendations.⁴¹

Study setting and selection of participants

We selected participants for the BCC and SCC focus groups from the three types of health centres providing dermatological care: academic hospitals (Erasmus MC), peripheral hospitals (Elisabeth-TweeSteden Hospital) and independent-sector treatment centres (DermaPark and Mohs Klinieken). One focus group for each diagnosis was organized at each type of health

centre, where electronic patient files were screened to select patients with a history of exclusively BCC or SCC. Additional information about the selection procedure can be found in Appendix S1 (see Supporting Information).

Data collection

Three focus group sessions were held with patients with BCC and three with patients with SCC. In total, 42 patients participated, varying from four to eight per group. The patients had a semistructured discussion about their needs and preferences regarding treatment and follow-up care. A topic guide was used to structure the discussion (Appendix S2; see Supporting Information). The topic guide originated from earlier experiences of the investigators and from theoretical grounds derived from the literature.^{17,42–45}

The sessions were moderated by an experienced moderator of focus groups [M.L., M.D. or Yesim Misirli (see Acknowledgments)] and were co-chaired by an independent dermatology-trained physician or dermatologist. The moderator explicitly stated that no consensus had to be reached and made sure that everyone was able to share their opinion, to prevent less confident participants from being constrained. All sessions were audiotaped and transcribed verbatim.

Data analysis

Two researchers (S.v.E. and M.L.) independently openly coded the first two transcripts using the qualitative software program ATLAS.ti 8-0 (ATLAS.ti, Berlin, Germany). The codes were discussed and adjusted when needed, which resulted in a preliminary coding scheme. The remaining four transcripts were coded by one researcher, then checked by the other. Different interpretations of codes were discussed and refined until agreement was reached. Data saturation was reached when no new codes (groups) were created in the third focus group of each diagnosis.

The analysis proceeded by the iterative and interpretive process of constant comparison, in which different codes were compared and the relationship between codes was explored to detect emerging themes. Separate code lists were created for patients with BCC and SCC to be able to identify differences and similarities between the groups. In case comparable themes emerged in the different focus groups, the same theme titles were used to enhance the visibility of similarities and differences between the groups of patients. The overall analytical process resulted in the identification of core themes and subthemes concerning the needs and preferences of patients with BCC and SCC regarding KC care.

Ethical considerations

The medical ethics committee of the Erasmus University Medical Center declared that the Medical Research Involving Human Subjects Act did not apply to this study and approved the study protocol (MEC-2016-204). Participation was on a

Table 1 Participants' characteristics

	Participants, n	Male, n (%)	Age (years), median (IQR)	Setting
BCC total	20	13 (65)	68.0 (60–78)	
Group 1	8	4 (50)	67.5 (54–74)	Academic hospital
Group 2	4	3 (75)	71.5 (60–82)	Peripheral hospital
Group 3	8	6 (75)	68.5 (67–77)	ISTC
SCC total	22	12 (55)	76.5 (70–82)	
Group 1	7	5 (71)	73.0 (70–82)	Academic hospital
Group 2	8	4 (50)	80.5 (76–85)	Peripheral hospital
Group 3	7	3 (43)	75.0 (69–80)	ISTC

IQR, interquartile range; BCC, basal cell carcinoma; SCC, squamous cell carcinoma; ISTC, independent-sector treatment centre.

voluntary basis and all patients participating in the study provided written informed consent.

Results

Needs and preferences of patients with basal cell carcinoma and squamous cell carcinoma regarding treatment and follow-up

The characteristics of the 42 participants are described in Table 1. Eight subthemes emerged from the data on the needs and preferences of both patients with BCC and those with SCC, and two additional subthemes were relevant only for patients with BCC. The findings and subthemes are described in detail below. Additional quotes illustrating each subtheme are presented in Appendix S3 (see Supporting Information).

Need for all relevant, tailored information and comprehensible explanation

Both patients with BCC and those with SCC mentioned the importance of receiving all information relevant to their treatment and follow-up, including a clear and comprehensible explanation. In this way they know what to expect and prepare for. Patients with BCC indicated an additional need for information on the disease background, preventative measures and all available treatments. Patients with SCC did not express this need. With respect to follow-up care, both patient groups mentioned that clear information on self-inspection would reduce the need for follow-up visits. They wish to receive information that is specifically tailored to their diagnosis and needs, preferably on paper.

'But I want to know what the background of that story is and I still don't know that. The only thing he keeps saying at the end of a discussion is it won't kill you. Yeah, okay.' (patient in BCC group 1)

Need for openness and transparency

Patients with BCC want openness and transparency from their physicians with respect to their prognosis, treatment options and follow-up policy. Not hearing about their prospects from their physician makes them feel insecure. They do not want their physician to withhold views or ideas about their situation and they want their physician to express when he or she is uncertain. Patients with SCC did not report this need.

'I would like to have more openness, that he tells what the possibilities are that we have further, and now that's still an open question, in two months we'll see again, think yes, don't you yourself have a vision that it's gone, or that something must happen again, the uncertainty remains.' (patient in BCC group 2)

Need for shared decision making

Patients with BCC want to contribute to the decisions regarding the management of their disease, for example in treatment decisions or in being treated by the type of physician of their preference. In contrast, some patients with SCC indicated explicitly that they do not want to be involved in shared decision making and would rather have their physician decide for them.

'The same as if at a given moment a physician says what do you think yourself, damn, and I answered, sir, you studied for that and maybe even at my expense, so should you ask me what it is, huh?' (patient in SCC group 2)

Need for a physician who listens, takes you seriously and communicates well

Patients from both groups reported the need for a physician who listens, takes you seriously and communicates well. Patients find it important to be able to tell their story to a new physician, even though it is well documented in their medical file. They prefer a personal approach from the physician as this creates trust.

'Yes, a doctor can be very skilled but not get along with people, that's a real shame, actually, because you have to trust, uh, that doctor.' (patient in BCC group 3)

Need for a short waiting period and to receive the best treatment with direct results

Patients with BCC and SCC mentioned the importance of being treated fast and to receive the best treatment with direct results. Patients want to have a short waiting period because they do not want to be in uncertainty for too long. They would rather have more skin removed than necessary in order to be tumour free in one session. Patients with SCC specifically preferred to

be treated by Mohs micrographic surgery, as this has the highest likelihood of giving a tumour-free result by the end of the day.

'If the biopsy was taken and they have confirmed it is SCC, okay, treatment within 14 days. That is what I think.' (patient in SCC group 3)

Need for continuity of care, to be seen by the same physician

Both patient groups expressed the need for continuity of care – to be treated by the same physician every time – so he or she will make the patient's problem his or her problem instead of passing the problem to another physician. Another reason is that they do not need to tell their whole story every time. In addition, they want a physician they can trust based on prior experiences. With respect to follow-up, some patients with BCC indicated that the physician who treated them should also be the one who performs the follow-up visits, because they gained trust in this physician. Patients with SCC did not express this need.

'Yes sure, I also return to the same dentist every time, to name a thing.' (patient in SCC group 3)

Preference for a dermatologist as a treating physician compared with a general practitioner, nurse practitioner or physician assistant

Overall, both patients with BCC and those with SCC prefer to be treated by dermatologists, as they are the experts specialized in skin care, as opposed to GPs, who are generalists. Furthermore, dermatologists have better equipment than GPs and have the option to ask for support from nurses or colleagues when needed.

'I indeed have more trust in specialized people, certainly if we're thinking in the direction that it is perhaps cancer, then I want to be where the specialist is.' (patient in BCC group 2)

However, some patients with BCC and SCC indicated that GPs might be involved in their treatment under certain conditions. According to some patients with BCC, GPs may perform certain tasks such as excising small tumours, especially because of the short waiting period for GPs, but only when they have received proper training. Some patients with SCC would let the GP perform the excision if it is superficial and the GP reassures them he or she is confident enough to do it. In addition, some patients with BCC would allow being treated by an NP or PA, but only under the conditions of sufficient training and experience and under supervision of a dermatologist. Patients with SCC reported not wanting to allow having their tumour excised by an NP or PA. They think their tasks should be limited to superficial treatments such as changing stitches or cleaning wounds.

'Basically, they are now being trained by the dermatologists, with a supervisor. So yes I would not have any problems with that I think, no.' (patient in BCC group 1)

Need for structured follow-up care

In general, both patients with BCC and patients with SCC prefer periodic follow-up visits, with a possibility to attend between visits when they discover new suspicious lesions. They believe it is too hard for them to distinguish age spots from cancer and cannot check their whole body themselves. Periodic follow-up visits create a feeling of being taken seriously and provide certainty. However, some patients with BCC believe that periodic follow-up visits are not necessary, as long as they have easy and quick access to a dermatologist whenever they detect new suspicious lesions.

'I find another problem that I can't see half of my body, and the dermatologist (...), under a good lamp, with good eyes, an assistant next to him, and there free and discussed back and forth, "what do you think" so to speak. And then I say the frequency, in my case, then once every half year I'd like to see him, even if I have no problems.'

Preference for a dermatologist for follow-up visits compared with a general practitioner, nurse practitioner or physician assistant

With regard to follow-up visits, both groups prefer to be seen by dermatologists, rather than by GPs, NPs or PAs, especially for the first visit after treatment. They believe dermatologists are the experts, whereas they have insufficient confidence in the knowledge and expertise of GPs.

'No, not by the general practitioner, he is still not the specialist, even if he acknowledged it, still a pat on the back for him but he is still not a specialist in that area.' (patient in SCC group 3)

However, some patients with BCC indicated that they would accept follow-up visits being performed by NPs or PAs, under the conditions that he or she is qualified and that the dermatologist feels confident enough to transfer the patient to them. Patients with SCC reported not wanting the GP to be involved in follow-up care. Some patients with SCC indicated that they see a possibility for going to the GP when they have a suspicious lesion in between the structured follow-up visits at the dermatologist.

'I mean that I come back to the dermatologist every half year myself but in the interim I might dare to leave it to my general practitioner, something like that.' (patient in SCC group 3)

Need for full-body skin examination during follow-up visits

Both patients with BCC and those with SCC expressed the need for a full-body skin examination. They want to have their whole skin checked during follow-up visits, as they cannot check their whole body themselves. Patients with SCC emphasized the importance of full-body skin examination because of their fear that the tumour can metastasize.

'She (dermatologist) only looked at my face, and I thought that was very strange because you can get metastases in your whole body, and she really only really looked at my face and really no further, but did feel the glands because...she says because as soon as there was something there we can also feel it in the thickened glands.' (patient in SCC group 3)

Discussion

This first in-depth exploration on the needs and preferences of patients with KC identified a range of themes, which could be used to organize skin cancer care that is more tailored to the needs and preferences of this large patient group.

The need for information has already been identified in previous qualitative KC studies.^{29,36,37} However, we found that both patients with BCC and patients with SCC emphasized the importance of receiving this information tailored to their specific situation and explained comprehensibly. Additionally, patients with BCC indicated a need for more extensive information with respect to their diagnosis, treatment and prognosis in order to participate actively in the decision-making process, whereas patients with SCC explicitly stated not wanting to be involved. This difference may be explained by the fact that patients with BCC are generally younger and probably in an overall better condition than patients with SCC,^{1,46,47} which is consistent with previous studies stating that older patients and patients with a lower level of perceived health are less likely to participate in shared decision making.^{48–51}

Both patient groups also expressed the need for a physician who listens, takes you seriously and communicates well. This makes patients feel valued, increases their self-worth and gives them a sense of control.⁵² Related to this was the need of patients to be seen by the same physician, at least for the treatment and first follow-up visit, because this increases the patient's trust in their physician.⁵³ The need of patients to receive tailored information, in some cases to participate in decision making and to have a physician they can trust, suggests that care should be more patient centred and more time should be invested in the patient–physician relationship.⁵³ Research has shown that patient-centred care leads to improved health outcomes.^{54,55}

It should be stressed that there were far more similarities than differences in preferences and needs between the BCC and SCC patient groups. In addition, qualitative studies with patients with melanoma and even patients with other types of

cancers have demonstrated many similar themes, for example the need for more information and lack of trust in their GP.^{35,56,57} Whereas some needs and preferences may be relevant to all types of patients (e.g. a general need for information), others may be more disease specific (e.g. the need for full-body skin examination) or related to the personal characteristics of the patients rather than the diseases themselves. Several studies have indeed shown that patient characteristics such as demographic variables, comorbidities, perceived health status and patients' attitude towards involvement of care are associated with patient preferences.^{58–60} Future (skin) cancer-related qualitative research could take this into account by specifically including subgroups like older patients or patients with certain comorbidities.

A limitation of our study is that we have included only patients who were treated by dermatologists. This may have led to selection bias in their preference for a dermatologist as a healthcare provider. As the role of GPs in BCC care is currently expanding,^{13–15} future focus groups may also be organized in a primary-care setting. By organizing six focus groups in different medical specialist settings, we were able to create a representative sample of patients with KC treated by dermatologists. However, the qualitative design does not allow us to draw conclusions on differences in the needs and preferences between patients from different medical settings.

Obviously, it is not possible in most healthcare systems to accommodate all the wishes of the patients, for example the preference always to be seen by a dermatologist. A recent discrete-choice experiment among low- and high-risk patients with BCC found that patients accept fewer follow-up visits and will have them performed by a GP if the first treatment evaluation is performed by the initial healthcare professional and if they receive a personalized information handout (Misirli, submitted for publication). An intervention study among patients with melanoma also showed that providing personalized information is more effective in increasing adherence to advice compared with giving generic information.⁶¹ Patients with melanoma were also found to accept fewer follow-up visits from a nonspecialist under certain conditions, such as increased continuity of care and rapid clinical review of anything causing concern.^{31,32} These trade-offs should be taken into account when developing future policies.

In conclusion, patients with KC expressed a set of specific needs and preferences regarding KC care. The new insights from our focus group study could be used to tailor skin cancer care according to the needs and preferences of these patients. This could be achieved by enhancing patient-centred care, for example by investing in the patient–physician relationship and by personalizing the type and form of information, the method of explanation and the follow-up schedules. In a continuation of this study, an initiative has already been started to investigate the effects of providing patients with BCC with a personalized handout on paper.⁶² With this handout we hope to reduce the pressure on the current healthcare system by reducing the need for low-value BCC follow-up visits, while increasing patient satisfaction. Adding the patient's

perspective to current guidelines on BCC and SCC could further improve the quality of skin cancer care.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Appendix S1 Selection of participants.

Appendix S2 Topic guide focus groups.

Appendix S3 Illustrative quotes.