

Patients highly value routine follow-up of skin cancer and cutaneous melanoma

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ABSTRACT

INTRODUCTION: Skin cancer follow-up is a substantial burden to outpatient clinics. Few studies have investigated patients' views on skin cancer follow-up and cutaneous melanoma. The objective was to investigate patients' perceived benefits and the impact of follow-up.

MATERIAL AND METHODS: This study included an open sample of patients attending routine follow-up at the outpatient Departments of Plastic Surgery and Dermatology, Roskilde Hospital. A total of 218 follow-up patients diagnosed with cutaneous malignant melanoma (MM), non-melanoma skin cancer (NMSC) or actinic keratosis (AK) completed a structured interview.

RESULTS: A total of 97% patients found follow-up useful. Continuity and consistency were important. One third of patients felt some degree of pre follow-up anxiety. The number of anxious MM patients was significantly greater than that of NMSC patients. No significant difference was found between the number of anxious MM and AK patients. Female gender, cohabitation and age younger than 50 years were associated with increased levels of anxiety. No relation was found between the number of anxious patients or the level of anxiety and the duration of the follow-up period.

CONCLUSION: The majority of patients who attended found that the follow-up had been useful. Certain demographic characteristics were associated with higher levels of anxiety and may be addressed by supportive efforts targeting these groups.

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Most patients diagnosed with cutaneous malignant melanoma (MM), non-melanoma skin cancer (NMSC) or actinic keratosis (AK) enter into routine follow-up after treatment. The main purpose of this follow-up is secondary prevention, i.e. early detection of recurrent disease and new primary tumours. Furthermore, follow-up consultations are intended to offer patient education and to reduce future risk of tumours [1, 2]. The incidence of both NMSC and cutaneous MM has increased substantially in all Caucasian populations [3, 4]. Follow-up of skin cancer patients therefore accounts for a substantial burden of outpatient capacity in skin cancer centres. Despite the good intentions for follow-up, the value of frequent skin cancer follow-up has been questioned.

It has been argued that regular follow-up might prompt unnecessary tests, raise anxiety and prolong the period of convalescence [5-7]; nevertheless, few studies have specifically investigated patients' views on skin cancer follow-up and most studies have focused on MM patients [1, 6, 8, 9]. We therefore decided to conduct a survey among skin cancer patients attending the outpatient Departments of Plastic Surgery and Dermatology for follow-up after treatment of skin cancer. Our aim was to investigate the patients' perceived benefits of follow-up and how skin cancer patients were affected by follow-up consultations.

MATERIAL AND METHODS

A structured interview was conducted among patients attending the outpatient Departments of Plastic Surgery and Dermatology at Roskilde Hospital, Denmark. Patients included in the survey were attending follow-up after treatment for cutaneous MM, basal-cell carcinoma (BCC), squamous cell carcinoma (SCC) or AK. All included MM patients had been radically treated for their primary cancer according to national guidelines. Patients with disseminated MM were not included in the study. The survey consisted of 14 questions and was formulated by the authors. Interview questions addressed issues concerning the perceived benefits of follow-up, the contents of the consultation and anxiousness prior to follow-up. All questions were based on issues raised in previously published work on follow-up [6]. All interviews were conducted by the leading author (LT) in accordance with the ethical guidelines of the 1975 Declaration of Helsinki. According to the availability of the interviewer, data were gathered on thirty-five days and follow-up patients were approached consecutively. All interviews were conducted in offices away from the doctors and staff involved in the follow-up consultations. Patients who did not speak Danish or could not participate in the interview due to poor general condition or amnesia were excluded from the survey.

Follow-up consultations were performed by physicians and had a scheduled duration of ten to fifteen minutes. For AK, BCC and SCC patients, follow-up consultations comprised examination of ultraviolet exposed skin. Patients with NMSC lesions located on unexposed parts of the body received full-body skin examination at every

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TABLE 1

Characteristics of follow-up patients interviewed.

	n	%
<i>Sex</i>		
Male	106	49
Female	112	51
<i>Outpatient department</i>		
Plastic surgery	127	58
Dermatology	91	42
<i>Cohabitation status</i>		
Cohabiting	153	70
Non-cohabiting	65	30
<i>Diagnosis</i>		
MM (cutaneous)	64	29
BCC/SCC	88	40
AK	43	20
MM + BCC/SCC ^a	7	3
BCC/SCC + AK ^a	15	7
MM + AK ^a	0	0
Other	1	0.5
<i>Duration of follow-up</i>		
< 1 year	54	25
> 3 years	65	30
Unaware	2	1

AK = actinic keratosis; BCC = basal cell carcinoma; MM = malignant melanoma; SCC = squamous cell carcinoma.

a) Patients diagnosed with a combination of two cancerous or pre-cancerous diseases.

follow-up consultation. Patients diagnosed with MM also received full-body examination, and lymph nodes were palpated at every consultation. All patients had received both written and verbal information about their disease, their individual prognosis and on sun behaviour. AK patients were informed that AKs are common precursors that rarely turn malignant. For both NMSC and MM patients, follow-up intervals depended on risk of recurrence, spreading and new primary tumours. Follow-up intervals could be shortened as required.

A total of 235 follow-up patients were approached. Out of these, eight patients were excluded and nine patients declined to participate in the study, which gave a total of 218 participants (response rate: 93%). Those who declined to participate uniformly gave time-constraints as their reason for declining. A total of 112 women and 106 men participated, with a median age of 69 years (range 23-95 years). Other characteristics of the follow-up patients interviewed are given in **Table 1**.

Data were anonymised, entered into a spread sheet and descriptive statistics were applied. Differences between discrete data were studied using contingency tables. Yates' correction was used where appropriate. Values of $p < 0.05$ were considered statistically significant.

Trial registration: not relevant.

RESULTS

A total of 97% patients found that follow-up consultations were useful (**Figure 1**). The main reasons for this were that patients felt reassured/well-examined (82%), they were examined for new cancerous disease (74%) and they had an opportunity to ask questions (73%) (multiple answers allowed). Only 10% found that consultations could be improved. One common subject for these patients was that doctors were not thorough enough when conducting the physical exam. This was stated by slightly more than 5%. The majority of the patients (69%) thought it was important or very important that follow-up consultations be performed by the same doctor every time, and 95% of patients replied that consultation length was always, or generally, adequate for their needs.

Approximately one third (31%) of all follow-up patients interviewed expressed some degree of anxiety before the visit (**Figure 2**). For 82% anxiety began just before, or in the days leading up to the follow-up visit. A third of the patients expressing anxiety in connection to follow-up visits also described having physical symptoms before the consultation. The most frequent complaints were sleep disturbance and stomach ache, which were described by 21% and 9% of the anxious patients, respectively (multiple answers allowed). Women were significantly more anxious than men ($p = 0.003$). Patients under the age of fifty were more anxious than patients over fifty ($p < 0.001$), and cohabiting patients were significantly more anxious than non-cohabiting patients ($p = 0.02$).

Figure 3 shows the percentage of anxious follow-up patients for each of the diagnoses MM, BCC/SCC and AK. The number of anxious MM follow-up patients was significantly greater than the number of anxious BCC/SCC patients ($p = 0.02$). No significant difference was found when comparing the number of anxious MM patients with AK patients ($p = 0.16$). This was also the case when comparing anxious BCC/SCC patients with AK patients ($p = 0.6$). No significant relation between the number of anxious patients or the level of anxiety and the duration of follow-up period was found.

There were no significant differences in patient perceptions between those receiving follow-up by plastic surgeons and those receiving follow-up by dermatologists. However, only BCC/SCC patients could be compared, as they were the only group receiving follow-up at both departments.

DISCUSSION

Almost all patients (97%) found that the follow-up consultations were useful, mainly because they felt reassured, they had the opportunity to ask questions and they were examined for new cancerous skin disease.

This correlates very well with the findings of other studies on patients' views of skin cancer follow-up [6, 8-10].

Our results confirm that follow-up patients attach great importance to the clinical examination [10-12]. The importance of clinical examination was emphasized both by patients satisfied with follow-up and by patients who were discontented with the consultations. In all, 5% of all follow-up patients did not feel adequately examined by the physician. These patients stated that the physical examination had not been performed thoroughly enough, that doctors should use palpation and dermoscopy more often, and that follow-up did not give them the desired reassurance. Similarly, a study on general practitioner-led MM follow-up found that patients valued a meticulous clinical examination highly. In line with this finding, seeing a specific doctor was highly appreciated and any lack of continuity was seen as a major disadvantage to follow-up conducted in a hospital setting [12].

One third of the patients expressed various degrees of anxiety prior to follow-up consultations. We found that the number of anxious MM follow-up patients was significantly larger than the number of anxious NMSC follow-up patients. This was an expected result given the difference in prognosis and the observation that a NMSC diagnosis has only little or no effect on patients-reported quality of life [13]. Interestingly, we found no significant difference between the number of anxious MM patients and AK patients or between the anxiety levels in the two groups. Sample size may have influenced the results, but other studies have also found AK patients to be anxious. Esmann & Jemec published a qualitative study on AK patients which suggested that these patients are anxious and concerned that their condition could worsen and develop into cancer [14]. Another study comparing the quality of life among NMSC and MM patients showed that NMSC patients were more concerned about the risk of scarring and disfigurement than MM patients were, while patients with MM were significantly more likely to mention "a sense of relief/gratitude following treatment and/or a commitment to enjoy life here on" [15]. The results may reflect how different concerns may produce similar end results. While MM patients may be concerned about a potentially fatal type of skin cancer, AK patients are concerned with skin cancer development in the future, which may potentially be more stressful than actually being diagnosed with NMSC.

The demographic characteristics we found to be associated with higher levels of anxiety were gender, age and cohabitation status. Women under the age of 50 appeared to be more anxious. In addition, we found that a significantly larger number of cohabiting follow-up pa-

FIGURE 1

Patients' views on follow-up services.

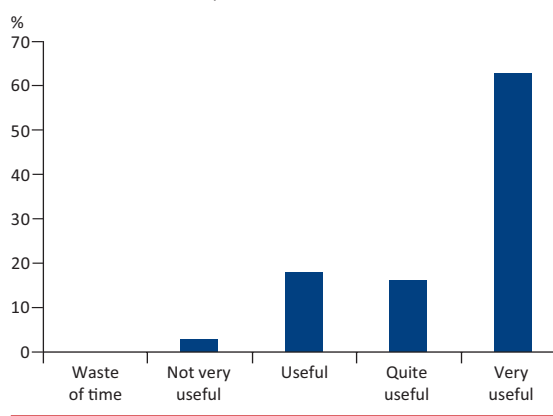


FIGURE 2

Patient anxiety related to follow-up consultations.

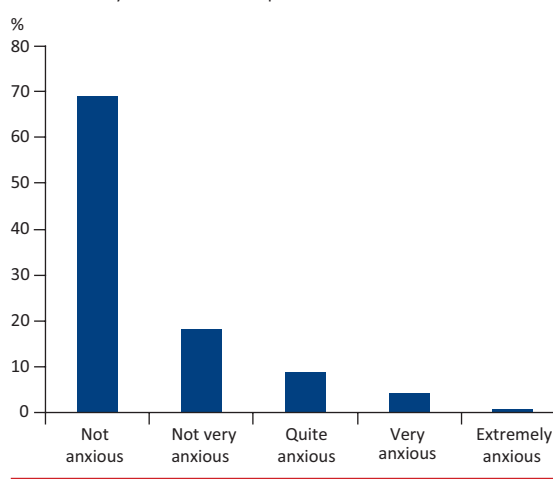
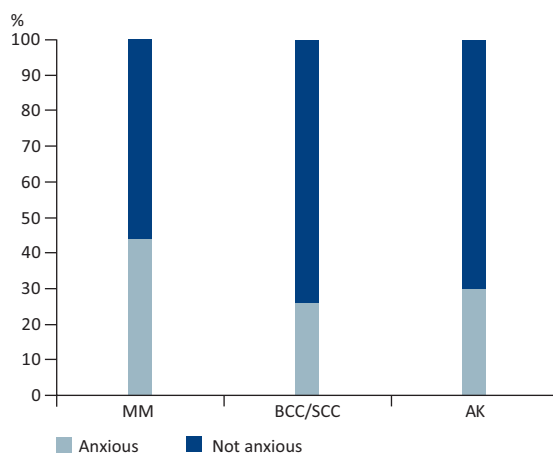


FIGURE 3

Percentage of anxious and non-anxious follow-up patients for each of the diagnoses. AK = actinic keratosis; BCC = basal cell carcinoma; MM = malignant melanoma; SCC = squamous cell carcinoma.





Skin cancer patients typically attend follow-up for several years after treatment.
Photo: Karsten Kanding Christrup.

tients were anxious compared with non-cohabiting patients. In relation to gender and age, other authors have found similar correlations between anxiety, female gender and young age [16, 17]. The reasons for this are unknown, but it is speculated that older patients might be less likely to become anxious because they have experienced a greater burden of disease than younger patients [16]. The correlation between anxiety and cohabiting patients is somewhat surprising. A qualitative study of AK patients found that some patients felt irritated and patronized when receiving overwhelming care and advice from family and friends in relation to their disease [14]. This could be an issue for cohabiting patients as well.

When looking at our results, it is also necessary to consider that the method of data collection may have affected the results. The structured face-to-face interview method used in this study is susceptible to interviewer effects, especially when questions about sensitive matters such as anxiety are raised. As a way of reducing the interviewer effects, fixed-worded questions were used in our survey and the interviews took place away from the offices where doctors and staff performed the follow-up consultations. We only included patients who attended follow-up, and it is therefore possible that patients who failed to appear for their consultations may have other views on routine follow-up. Patients who miss their outpatient appointments, however, receive a notification letter with a new scheduled appointment and it is our clear impression that only few skin cancer patients drop out of the scheduled follow-up programme.

Interestingly, no significant relation between the number of anxious patients or level of anxiety and the

duration of follow-up period was found. In our study, we did not investigate the physical location of the tumours, the recurrence rate or the rate of new primary tumours in interviewed patients during their follow-up period. It may be speculated that detection of recurrent disease or new primary tumours during the follow-up period can re-induce anxiety or concern. This may be a contributing factor in sustaining anxiety or concern during the follow-up period.

A study by Morton et al based on semi-structured interview questions with MM patients undergoing long-term follow-up found that anxiety prior to examinations was stated as a common downside of follow-up. One of the most substantial patient-perceived benefits of follow-up was, however, the reassurance patients felt after seeing a skin specialist, and patients valued the information and psychosocial support they received during follow-up highly [9]. Others have found that regular follow-up consultations do not appear to have negative psychological or psychosomatic effects [17, 18]. This correlates well with our findings. Although a third of the patients expressed some degree of anxiousness prior to follow-up, the majority of MM, NMSC and AK patients still felt reassured by the follow-up examination and thus found it useful and worthwhile. The importance of informing patients about the benefits and limitations of follow-up should be emphasised as a possible way to reduce anxiety in connection with follow-up [9].

Our study suggests that the prognosis of a disease does not per se determine the level of anxiety prior to follow-up consultations. The results also indicate that demographic characteristics such as female gender, age under 50 and cohabitation are associated with higher levels of anxiety. Additional supportive efforts directed at these groups may therefore be the most rational approach in an effort to reduce pre follow-up anxiety and concern, and to optimize the patient-perceived benefits of follow-up.

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