

Patient Perception of the Diagnosis Announcement and its Impact on Quality of Life of Patients with Primary Melanoma or Basal Cell Carcinoma

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An improved understanding of the impact of skin cancer on patients' daily life may optimize disease management. This questionnaire survey of adult patients in real-world settings aimed to assess patient perception of the diagnosis announcement, and the impact of the diagnosis on the patients' professional and personal life. Data from 355 patients with melanoma and 320 patients with basal cell carcinoma (BCC) were analysed. Melanoma significantly impacted the couple, and sexual relationships, as well as family and social life, and reduced the patient's libido more significantly than did BCC (all $p < 0.05$). Melanoma and BCC significantly impacted the patients' professional and personal lives. The word "cancer" used for a BCC announcement has a high anxiety-producing meaning for the patient. The announcement of each skin cancer should be made during a dedicated consultation, with more time devoted to the patient and with specific empathy, in order to improve reassurance of the patient.

Key words: basal cell carcinoma; quality of life; professional life; private life; fears; perception.

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Over the last decades, skin cancers have become the most frequent type of cancer in the Caucasian population and their incidence has increased continuously (1, 2).

Among the different types of skin cancer, melanoma skin cancer (MSC) is the least frequent skin cancer, representing 3.8% of cancers overall and 10% of skin cancers (3, 4). The mean age of patients at the time of diagnosis with MSC is approximately 64 years for women and 61 years for men. The prognosis for MSC is opposed to that of basal cell carcinoma (BCC), as the tumour may metastasize and even lead to death, with a mortality rate, according to French health authorities of approximately 1.2 women and 1.7 men/100,000, which has increased slightly over recent years (3, 4). Furthermore, even if optimal therapy is initiated early, the risk of relapse persists several years after diagnosis of MSC.

SIGNIFICANCE

Melanoma and basal cell carcinoma have a significant impact on patients' lives. Cancer announcements should be made during a dedicated consultation with specific empathy, in order to improve the reassurance of patients.

Conversely, BCC is the most prevalent, accounting for almost 75% of all skin cancers. The mean lifetime risk for white-skinned individuals to develop BCC is approximately 30% (1). The prevalence of BCC increases with age, but it remains rare in patients under the age of 40 years. The prognosis of BCC is good, and treatment consists mainly of excision under local anaesthesia. BCC may not be considered as a life-threatening cancer, as it is a local lesion and the risk of metastases and death is very low (3). However, due to its location on photo-exposed areas (mainly on visible zones of the face and neck) and the risk of scarring associated with surgery, treatment of BCC may heavily impact the patients' well-being and alter their relationships with other people (5).

In the area of cancers, in general, concomitantly to the physical impact of the disease and of the treatments, a significant proportion of patients also experience psychological distress and burden requiring adjunctive or specific procedures, such as psychological support, because all cancers are thought to be life-threatening (5). This could also be the case for skin cancers. Thus, it is important for dermatologists providing care to patients with skin cancer to consider the psychological impact of the condition in order to help patients deal with their fears and concerns.

To the best of our knowledge, there are no published studies comparing the perception of cancer diagnosis announcements for both patients with MSC and those with BCC. The aim of this survey study was to compare the perception of diagnosis announcements and their consecutive impact on the professional and personal lives of patients with MSC or BCC.

METHODS

A cross-sectional quantitative-survey performed in real-world settings was conducted by both the French Society of Dermato-

logy (SFD) and the French Federation of Continued Education and Evaluation in Dermatology and Venereology (FFCDV) in France. All dermatologists in private practice or at hospital sites (3,800 dermatologists) were invited to participate in the survey. Patients of at least 18 years of age with a history of skin cancer or with a newly diagnosed skin cancer were considered eligible for participation.

According to the French legislation at the time the survey was conducted, no approval from competent health authorities or ethics committee was required. However, patients who were willing to participate received written information about the survey and signed a non-opposal form.

The survey included 2 questionnaires for each skin cancer situation (Appendix S1); 1 to be completed by the dermatologists and 1 by the patients. The dermatologists completed a questionnaire about skin cancer characteristics during consultation and distributed a second questionnaire to be completed by selected patients at home, following the consultation, which they had to return within 15 days. The physician's questionnaire collected data about age and sex, skin cancer history at the time the questionnaire was completed, as well as main comorbidities and general health condition according to Eastern Cooperative Oncology Group/World Health Organization Performance Status (ECOG/WHO PS) with a scale of assessment ranging from 0 "normal activity" to 5 "death" (6). The patient questionnaire collected data about their feelings, fears and perceptions at the time of the first announcement of the diagnosis of skin cancer and assessed the medical care performed. It also recorded health insurance coverage, private (married, children) and professional situations, as well as consequences of skin cancer on professional and private lives (i.e. tiredness, food, leisure, sun exposure and sport habits). The perception of diagnosis announcement and fears, as well as the impact on both professional and private lives were compared between patients with MSC and BCC.

Both questionnaires were developed and validated by a designated scientific committee of the SFD, including experts in skin cancer, a psychologist and patient representatives. The questionnaires were designed to collect data about the patients' experience, and focused on the patient-centred approach. All questions were specifically designed to capture the impact on the patients' daily life. Questionnaires were structured with a certain number of questions, to which patients could answer with "Yes" or "No", other questions required the respondent to choose between "Yes", "No" or "I don't know", while some other questions had 5 possible answers ("None", "No", "A little", "Moderately", "Enough" or "A lot"); no question had an open design.

To obtain meaningful data, the questionnaires were sorted into homogeneous groups by classifying patients by cancer type, including a group of patients with localized melanoma, and a group of patients with BCCs. The remaining patients had carcinoma *in situ* or squamous cell carcinoma, actinic keratoses, metastatic melanoma, or a rarer tumour, and data from these patients were not used for this study.

Statistical analysis was performed using SAS version 9.4 (SAS Institute, NC, USA). The risk was set at 0.05. A descriptive and inferential analysis was performed. A descriptive analysis was made for qualitative and quantitative variables. An inferential analysis was performed using the χ^2 test for related items; otherwise, the Fisher's exact test was used. The comparison of several variables was tested using the Student's *t*-test if variables were considered normal and if homoscedasticity was respected; otherwise, the Kruskal–Wallis test was applied.

RESULTS

The survey was conducted between June and October 2017. Of the 3,800 dermatologists contacted, 382 agreed to participate, corresponding to a participation rate of 11.3%. Of these, 74.4% consulted in private practice and 25.7% in hospital facilities.

Overall, 1,890 patients participated in the survey, and all consented to participate. In order to be included in the analysis, both patient and investigator questionnaires had to be completed for a given patient. A total of 718 patients did not return the questionnaire; hence only 62.0% (1,172) of questionnaires were suitable for analysis.

To enable recruitment of a large number of patients, questionnaires were addressed to all patients with skin cancer with no distinction. Therefore, 497 patients with actinic keratoses, carcinomas *in situ*, BCCs, squamous cell carcinomas (SCCs), localized MSCs, and other rarer tumours, such as dermatofibrosarcoma protuberans were also recruited, but not eligible for the data analysis.

Patient demographic and socio-demographic data

Overall, data from 675 patients were analysed. Of these, 355 patients had a diagnosis MSC, 55 at the initial diagnosis (localized MSC stage, without metastasis), and 300 during the follow-up of a pre-existing, surgically resected and non-relapsed MSC; 62.6% of the patients were recruited by hospital dermatologists. The BCC group included 320 patients, of whom 76.8% were recruited by dermatologists from private practice.

Patients in the MSC group were younger (60 ± 13 years) than those in the BCC group (68 ± 12 years); the difference

Table 1. Patient characteristics

	MSC (total <i>n</i> = 355)	BCC (total <i>n</i> = 320)	<i>p</i> -value
Gender, % (<i>n</i>)			
Male	48.2 (162/336*)	53.0 (161/304*)	0.2304 ^a
Female	51.78 (174/336*)	47.0 (143/304*)	
Age, years, mean \pm SD	60.0 \pm 13	68 \pm 12	< 0.0001 ^c
Personal situation, % (<i>n</i>)			
Single	20.0 (68/339*)	26.8 (82/306*)	0.079 ^b
Relationship	79. (269/339*)	71.6 (219/306*)	
In institution	0.3 (1/339*)	1.0 (3/306*)	
Other	0.3 (1/339*)	0.6 (2/306*)	
Having dependent children, % (<i>n</i>)	54.6 (101/185*)	36.1 (52/144*)	0.0009 ^a
Professionally active, % (<i>n</i>)	41.6% (143/344*)	22.0 (68/300*)	< 0.0001 ^a
Health coverage, % (<i>n</i>)			
National health coverage	97.4 (305/313*)	95.00 (285/300*)	0.1114 ^a
Long-term health coverage for skin cancer	65.7 (211/321*)	14.4 (38/264*)	< 0.0001 ^a
Family history of skin cancer, % (<i>n</i>)	20.6 (69/335)	26.5 (78/294*)	0.0793*
Comorbidities significant, % (<i>n</i>)			
None	83.7 (297/355)	75.6 (242/320)	0.0093^a
Age (> 80 years)	4.2 (15/355)	3.4 (11/320)	0.0595 ^a
Anticoagulating treatment	4.5 (16/355)	12.8 (41/320)	0.0001^a
WHO-5, % (<i>n</i>)			
WHO=0	92.7 (329/355)	93.2 (290/311*)	0.2915 ^b
WHO=1	5.3 (19/355)	4.5 (14/311*#)	
WHO=2	2.0 (7/355)	1.3 (4/311*)	
WHO=3	0 (0/355)	1.0 (3/311*)	
WHO=4 or 5	0 (0/355)	0 (0/311*)	

^a χ^2 test. ^bFisher's exact test. ^cKruskal–Wallis test.

*Patients with available data.

MSC: melanoma skin cancer; BCC: basal cell carcinoma; SD: standard deviation. Bold *p*-values indicate significance.

Table II. Fears and concerns of the patient at the time of first cancer diagnosis announcement

	MSC (n = 355) % (n)	BCC (n = 320) % (n)	p-value
Patients who experienced trauma/stress were shocked by the first announcement of the diagnosis	66.8 (219/328*)	36.1 (104/288*)	<0.0001^a
Patient who immediately feared that an "evolution" of the disease could occur	72.8 (244/335*)	46.6 (138/296*)	<0.0001^a
Patient who immediately feared that a generalization of the disease could occur	57.6 (193/335*)	27.1 (78/288*)	<0.0001^a
Patient who was afraid of dying of skin cancer	44.7 (149/333*)	11.9 (34/286*)	<0.0001^a
Patients who discussed the diagnosis with their partners	93.5 (288/308*)	89.7 (236/263*)	0.1668^b
Patients who discussed the diagnosis with their children	79.4 (247/311*)	73.3 (203/277*)	0.1972^a
Patients who discussed the diagnosis with their friends	74.7 (248/332*)	61.0 (175/287*)	0.0004^a
Patients who discussed the diagnosis with their professional relationships	48.3 (127/263*)	26.3 (59/224*)	<0.001^a

^aχ² test. ^bFisher's exact test.

*Patients with available data.

MSC: melanoma skin cancer; BCC: basal cell carcinoma. Bold p-values indicate significance.

was significant ($p < 0.0001$). Significantly ($p < 0.0001$) more patients with MSC (41.6%) were professionally active compared with those with BCC (22.0%), and significantly ($p < 0.0009$) more patients with MSC had children they had to take care of (54.6%) compared with 36.1% of patients with BCC. Overall, more than 90% of all patients in both groups were of very good general health according to the ECOG/WHO PS scale, 92.7% with a ECOG/WHO PS scale score of 0 in the MSC group and 93.2% in the BCC group. Detailed patient characteristics are shown in **Table I**.

Patient perceptions of the diagnosis and fears at the time of the first announcement of a cancer diagnosis by the dermatologist

At the time of initial diagnosis 66.8% of patients with MSC reported that they were "shocked" (experienced stress or trauma) compared with 36.1% of patients with BCC; the difference was statistically significant ($p < 0.0001$) when answering the question "were you immediately hurt, shocked at the initial announcement".

Furthermore, significantly more patients with MSC (79.9% ($n = 195/244$), $p < 0.001$) reported being bothered by scars and aesthetic problems caused by the surgical treatment compared with 66.7% ($n = 158/237$) of patients with BCC. These scars caused significantly ($p < 0.001$) more pain, impacting the daily life of 48.3% ($n = 116/240$) of patients with MSC, compared with BCC 28.6% ($n = 68/238$). Detailed results are shown in **Table II**.

Impact on professional life

In total, 41.6% of patients with MSC were professionally active compared with 22.0% of patients with BCC. With regards to the impact on professional life, the absence from work within the previous 6 months was 28 days for the MSC and 15 days for the BCC groups, respectively. Even though an obvious

impact on professional life was observed in both groups, there was no significant reason for absence, changes in working conditions or reduction in income. Moreover, 20.3% of patients with MSC experienced problems in obtaining a bank loan, compared with 6.0% (3/50 patients with available data) of patients with BCC; the difference was statistically significant ($p = 0.0363$). The detailed results are shown in **Table III**.

Impact on private life

MSC and BCC impacted the patients' private life differently. Patients with MSC isolated themselves ($p < 0.0001$), felt discouraged ($p < 0.0001$), tired ($p < 0.0001$), tense ($p < 0.0001$) depressed ($p < 0.0001$) and alone ($p < 0.0019$), and had difficulties falling asleep ($p < 0.0001$) significantly more often than patients with BCC. MSC impacted the couple ($p = 0.0477$) and sexual relationships ($p = 0.0013$) significantly more, reduced libido ($p = 0.0017$) significantly more and impacted family ($p = 0.0014$), social ($p = 0.0003$) and professional lives ($p = 0.004$) significantly more than BCC. Moreover, MSC not only impacted the patients' life and relationships, it also significantly impacted their lifestyle, concerning food ($p = 0.0079$) and sports habits ($p = 0.1097$).

Table III. Respective impact of melanoma (MSC) and basal cell carcinoma (BCC) on the professional life in professionally active patients

	MSC (total n = 143)	BCC (total n = 68)	p-value
Patients missed working days over the last 6 months	42.0 (58/138*)	28.6 (18/63*)	0.1101 ^b
Unplanned absences at work, % (n)	40.7 (22/54*)	31.2 (5/16*)	0.4933 ^a
Number of days stopped, mean ± SD	28 ± 54	15 ± 25	0.2838 ^c
Reason for absence, % (n)			
Medical appointment	79.3 (46/58*)	61.1 (11/18*)	0.1319 ^b
Cancer treatment	41.4 (24/58*)	50.0 (9/18*)	0.5192 ^a
Important fatigues due to cancer	8.6 (5/58*)	5.5 (1/18*)	1.0 ^b
Need to stay alone	5.2 (3/58*)	5.5 (1/18*)	1.0 ^b
Patients had to adapt working hours, % (n)	14.5 (18/124*)	3.9 (2/51*)	0.1237 ^b
Patients had to ask for a therapeutic part-time work, % (n)	8.1 (10/124*)	0 (0)	0.0781 ^b
Patients having experienced a loss of efficacy at work, % (n)	21.9 (27/123*)	14.0 (7/50*)	0.4347 ^b
Patients having experienced an income loss, % (n)	8.9 (11/123*)	6.0 (3/50*)	0.576 ^b
Patients having met difficulties to obtain a loan, % (n)	20.3 (25/123*)	6.0 (3/50*)	0.0363^a

^aχ² test. ^bFisher's exact test. ^cKuskal-Wallis test.

*Patients with available data.

Patients had to choose from 5 possible answers: "never", "rarely", "sometimes", "often" and "very often". The percentages reported in this sub-section corresponded to all patients who answered "sometimes", "often" or "very often". Bold p-values indicate significance.

Finally, 90.4% of patients with MSC and 92.8% with BCC modified their habits regarding sun exposure ($p=0.328$). Detailed results are shown in **Table IV**.

DISCUSSION

The aim of this study was to compare the perception and fears associated with the diagnosis announcement at the initial diagnosis, and to examine the subsequent impact of this announcement on the professional and private lives of patients with MSC and BCC.

The announcement of MSC or BCC, regardless of its prognosis, was perceived as "inducing a shock".

While 66.8% of patients with MSC were "shocked" at the diagnosis, being consistent with the general public's knowledge of the metastatic risk of melanoma, it should be noted that 36.1% of patients with BCC also experienced their diagnosis as "traumatic" and almost half of them were frightened about metastatic progression or the risk of dying from BCC, because they retained that the dermatologist used the word "cancer" for the skin condition. It is important to note that this survey included only excised and non-relapsed MSC, representing stage I, II or III MSC, based on the American Joint Committee on Cancer (AJCC) classification (7).

The current results confirm observations made by Burdon-Jones et al. (8), emphasizing the importance of announcing the diagnosis.

Results confirmed that the perception of the announcement of a diagnosis of a skin cancer was not associated

with any particular type of skin cancer, but only with the word "cancer" itself. Another study characterized factors contributing to cancer worry in the skin cancer population and showed that cancer worry was not associated with skin cancer type (9).

There is clearly a need to clarify and downplay the diagnosis and the information given in the context of the announcement of a diagnosis, in order to reduce anxiety and distress. This requires time and empathy in the patient-physician relationship. The dermatologist's empathy is therefore key. The need for the patient to obtain all relevant information about BCC, as well as a preference for a physician who takes the patient's fears into consideration and who communicates well were already highlighted in a previous publication, which identifies the needs and preferences of patients with BCC and SCC (10).

Winterbottom et al. (11) explored patients' early experiences of skin cancer (BCC and MSC), including how they cope with the diagnosis. Patients with BCC reported that, when clear information was provided, they felt little cause for concern. Conversely, they expressed anxiety when the diagnosis was not clearly presented.

Both, MSC and BCC impact the professional and private lives. Despite its non-relapsing characteristics and legal regulations, patients with primary/non-relapsing MSC had significant problems in obtaining a bank loan, which may be related to the symbolism of the severity of the disease and its poor prognosis. MSC impacts the patients' daily life and well-being, and may cause fatigue and depression, sometimes years after the initial diagnosis, as reported by more than 15% of patients with MSC (12). In the current survey, 62.5% of patients with MSC reported feeling tired, tense (67.3%), depressed (53.1%) or isolated (34.3%). These figures confirm results obtained by Trask et al. (13). This could explain the consequences on the libido and sexual activity being more marked for patients with MSC.

Almost one-third of patients with BCC reported feeling tired, tense or depressed. These results may be surprising, considering that BCC is considered by dermatologists as "benign, common" most of the time. They are consistent with another study, which observed a significant impact on the daily life of patients with BCC (14).

Patients massively declared that they had changed their behaviour concerning sun exposure, similarly to previous publications (14). In the current survey, one-third of all patients modified certain hobbies or sport activities, probably in order to reduce their sun exposure, similarly to previous studies with more than half of all patients taking fewer holidays in sunny regions (15).

Moreover, 79.9% of patients with MSC and 66.7% of patients with BCC reported consequences of cancer management with scars or aesthetic

Table IV. Respective impact of melanoma (MSC) and basal cell carcinoma (BCC) on the patient's private life

	MSC (n = 355)	BCC (n = 320)	p-value ^a
Impact of skin cancer on couple and on familiar and social relationship, % (n)			
Patient perceived			
Lacking time to take care	29.4 (65/221*)	21.9 (43/196*)	0.0874
Altered relationship in the couple	16.4 (33/201*)	9.3 (15/161*)	0.0477
Sexual relationship affected	34.9 (66/189*)	19.3 (30/155*)	0.0013
Decreased libido	43.2 (86/199*)	27.2 (43/158*)	0.0017
Patient perceived a negative evolution of			
Familiar relationship	15.4 (36/234*)	5.5 (10/182*)	0.0014
Social relationship	15.4 (35/227*)	4.4 (8/181*)	0.0003
Professional relationship	17.9 (28/156*)	6.1 (7/115*)	0.004
Impact of skin cancer on the patient him/herself, % (n)			
Patient had			
Tendency to isolate him/herself	44.3 (109/246*)	24.7 (51/206*)	< 0.0001
A feeling of discouragement	47.1 (116/246*)	23.4 (49/209*)	< 0.0001
Difficulties falling asleep	61.9 (159/257*)	36.7 (78/212*)	< 0.0001
Patient felt			
Tired	62.5 (157/251*)	37.7 (81/215*)	< 0.0001
Tensed	67.3 (169/251*)	37.4 (80/214*)	< 0.0001
Depressed	53.1 (135/254*)	31.1 (66/212*)	< 0.0001
Alone	34.3 (86/251*)	20.6 (44/214*)	0.0019
Impact of skin cancer on the patients way of life, % (n)			
Patients			
Modified their habitudes to sun exposure	90.4 (226/250*)	92.8(221/238*)	0.328
Modified their nutrition habitudes	11.8 (28/238*)	4.7 (10/210*)	0.0079
Abandoned certain type of leisure	36.4 (90/247*)	28.6(59/206*)	0.0786
Abandoned certain types of sport	36.3 (81/223*)	25.6 (49/191*)	0.0197

^a χ^2 test.

Patients had 5 possible answers: "never", "rarely", "sometimes", "often" and "very often". The percentages reported in this sub-section corresponded to all patients who answered "sometimes", "often" or "very often". Bold p-values indicate significance.

problems. Although these side-effects are unavoidable, scars caused significant pain or discomfort in daily lives in 48.3% of patients with MSC and 28.6% of patients with BCC. These post-operative symptoms are probably perceived by all patients affected as unavoidable in the context of a primary skin cancer. However, these symptoms should not be underestimated by the physician, especially as they may often last a long time (16).

Limitations and strengths

The main limitation of this survey study was its declarative design. The majority of the results do not have any measurement means. Moreover, it did not consider the time at which cancer treatment was initiated, which may have an important impact on the patients' responses. Another important limitation is the fact that only 11.3% of all French dermatologists participated in this study. However, not all French dermatologists are necessarily involved in skin cancer or may wanted to respond to this type of time-consuming survey, which may explain the low response rate. Likewise, this study did not consider the fact that certain patients might have had several carcinoma prior to participating in the survey, and that this element might have influenced the responses compared with a patient having experienced the disease for the first time. Furthermore, the localization of the skin cancer was not considered for analysis purposes. However, whatever the localization of the tumour, patients were impacted by the aesthetic risk of scars. Furthermore, the tumour-node-metastasis (TNM) status of the tumour and its aggressiveness (primary tumour, advanced or metastatic stage and/or Breslow thickness) for both MSC and BCC were not considered in the questionnaire. However, the dermatologist had to specify in the questionnaire whether the patient was recruited during the medical care or follow up, and had to report the treatment of the tumour (surgery, radiotherapy or medical treatment, such as immunotherapy or targeted therapy). Based on this information, only patients with primary and non-relapsed MSC were selected for the current survey, as we considered this the most relevant information to assess impact on quality of life.

The survey results may be considered biased, as questionnaires were distributed only to patients who were in good general health, and capable of responding. However, the relatively high response level of 62% confirmed the patients' interest in this issue, especially when completing a questionnaire lasting 30 min on average. Even though, a certain number of patients did not respond exhaustively to all of the questions, resulting in a large amount of missing data. This can be explained by the fact that the questionnaire may be considered too long, or sometimes questions were misunderstood, or even reflect a lack of interest if the patient did not feel concerned by a specific question.

Despite these limitations and bias, we consider that the results of this study are of interest. The questionnaires used were both standardized and previously validated

by experts, were exhaustive, and enabled us to assess the psychological impact of 2 different skin cancers with different prognoses, which, to our knowledge, has never been done previously.

Finally, the large proportion of dermatologists who participated in this survey reflects the interest of the medical community.

Conclusion

MSC and BCC have a significant impact on patients' professional and personal lives. The term "cancer" used for a BCC has a strong anxiety-producing meaning for the patient. Its announcement should be made during a dedicated consultation, with more time devoted to the patient and with specific empathy to improve reassurance of the patient.

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