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“What is it about your skin cancer that bothers you the most?” 700 patients respond

S.K. Grewal¹, M.M. Chren^{2,3}, R. Parvataneni², S.E. Stuart², E. Galles⁴, and E.L. Linos²

¹The Commonwealth Medical College, Scranton, Pennsylvania

²Department of Dermatology, University of California San Francisco

³San Francisco Veterans Affairs Medical Center, San Francisco

⁴Carver College of Medicine, University of Iowa

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Dear editor

Typical basal cell and cutaneous squamous cell carcinomas (Non-melanoma skin cancers or Keratinocyte carcinomas, KCs) are not lethal, but whether and how they affect patients' wellbeing is poorly understood.^{1,2} The goal of this study was to understand how KCs bother patients prior to treatment.

Data were collected from a consecutive cohort of all 1,536 patients with 1993 histologically confirmed KCs diagnosed in the Dermatology clinics at the University of California, San Francisco or the San Francisco Veterans Affairs Medical Center in 1999–2000. Patients with Basal Cell Nevus Syndrome were excluded. The design of this prospective cohort study has been described and was approved by the University of California, San Francisco institutional review board.³ This analysis was limited to patients who responded to a questionnaire about their skin cancer before it was treated, but typically after patients knew their diagnosis (N=897 patients with 1164 tumours). Of these, 764 patients (85%) responded to the question “Overall, during the past week, how often have you been bothered by your skin problem?” Patients responded on a Likert scale from 1 to 7; we empirically defined responses 1–2 as mild, 3–5 as moderate and 6–7 as severe. Seven hundred patients (78%) answered the open-ended question “What is it about your skin problem that bothers you the most?” Since patients could list multiple causes of bother (e.g. appearance and itching); there were 868 distinct causes of bother among the 700 patients who responded. Using explicit definitions of bother, two authors (SG and EL) independently classified the causes of bother into 8

Corresponding Author: Eleni Linos, BM, BCh, DrPH, UCSF Dermatology, 2340 Sutter Street San Francisco, CA 94143, linose@derm.ucsf.edu; Phone: 415-502-0433; Fax: 415-476-6751.

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categories: concerns about prognosis, cosmetic concerns, physical symptoms, concerns about procedures, inconvenience, administrative issues, emotional, and functional limitations. Discrepancies in classification were compared and discussed to reach agreement; if disagreement persisted, a third author (MC) was the final arbitrator of classification.

Overall, 46% of patients were moderate to severely bothered by their skin cancer. 27.3% of patients (245/897) were moderately bothered (3–5 on Likert scale) and 18.6% (167/897) were extremely bothered by their skin condition (6–7 on Likert Scale). Specific examples of causes of bother in patients' own words are included in Table 1. The most common cause of bother was concerns about prognosis (36%), followed by cosmetic concerns (16%), and physical symptoms (12%), including itch (5.5%), bleeding (2.0%), pain (1.6%), dryness (1.6%), burning (1.3%). Patients also expressed concerns about procedures (8%), inconvenience (6%), and administrative (2%), emotional (1.5%) and functional limitations (1.3%) (Figure 1). Itch was the most common physical symptom, reported by 5.5% of patients overall. 9 patients (1%) expressed fear of death while 31 patients (3.5%) were concerned about melanoma.

In conclusion, we found that approximately half of patients were at least moderately bothered by their KCs before treatment. The most common physical symptom reported was itch, consistent with prior studies.⁴ The most common causes of concern overall included concerns about prognosis, cosmetic concerns, and physical symptoms. A small number of patients were also concerned about melanoma and death from skin cancer.

These results illustrate that many KCs bother patients, and suggest that patients' experiences of KCs could be improved by better patient education. Specifically, we recommend that clinicians address patients' concerns about prognosis including risk of recurrence and subsequent new tumors, and explicitly state that these cancers are different from melanoma, when discussing diagnosis of KC with their patients.

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Figure 1.
Categories of responses to “What is it about your skin cancer that bothers you the most?”

Table 1

Categories and example responses to “What is it about your skin cancer that bothers you the most?”

Category	N	%*	Examples (in the patient's own words)
Concerns about prognosis	321	35.8	That it may turn into a more serious form of cancer That it will progressively get worse How many more will I have?
Cosmetic concerns	146	16.3	Wondering if it would leave a scar It might change my looks
Physical Symptoms	107	11.9	Itching Getting sore Burning
Concerns about procedures	67	7.5	Having Mohs surgery almost every month The possible need for plastic surgery Not swimming after procedure
Inconvenience	56	6.2	Having to go to see my dermatologist over & over Not being able to be outdoors in the sun
Administrative	15	1.7	The difficulty of getting an appointment to have it treated Missing work
Emotional	13	1.5	I've been depressed Makes me feel unattractive It's much more disturbing than I could have anticipated
Function	12	1.3	Interrupting my sleep Blindness as a result of radiation therapy Location on penis- it interferes quite a bit with my relationship
Other	131	14.6	