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Patient experiences and outcomes following facial skin cancer surgery: a qualitative study

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Abstract

Early melanoma and nonmelanoma skin cancer of the facial area are primarily treated with surgery. There is little known about patient outcomes of the facial skin cancer population. The objective of the study was to identify aesthetic, procedure and health-related concerns from the patient's perspective after facial skin surgery. Semi-structured in-depth interviews were conducted with 15 participants. Line-by-line coding was used to establish categories and develop themes. We identified five major themes related to the impact of skin cancer surgery: appearance-related concerns; psychological function (e.g. fear of new cancers, recurrence); social function (e.g. impact on social activities and interaction); adverse problems (e.g. pain, swelling) and satisfaction with the experience of care (e.g. satisfaction with surgeon). The priority of participants was the removal of the facial skin cancer as this diminished their overall worry. The aesthetic outcome was secondary but important as it had important implications on the participant's social and psychological functioning. The participant's experience with the care provided by the surgeon and staff also contributed to treatment satisfaction. This conceptual framework provides the basis for the development of a new patient-reported outcome (PRO) instrument.

Introduction

Skin cancer of the head and neck area is often treated with excisional or Mohs micrographic surgery. Treatment effectiveness has traditionally focused on morbidity and mortality, however the patient's perspective is increasingly considered integral. Patient-reported outcome (PRO) measures are questionnaires where responses are collected directly from patients. They provide a means of quantifying the way patients perceive their health and the impact of treatment on their quality of life.[1]

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Patients that undergo surgical treatment for skin cancer are left with varying degrees of scarring. In a study of nonmelanoma skin cancer (NMSC) patients, more than half had concerns about the scar appearance, yet scarring is often minimally addressed.[2,3] In a systematic review of PRO instruments, the Skin Cancer Index addressed appearance concerns but was not specific to the facial area.[4] The POS-Head/Neck was developed for surgical procedures of the head/neck area; however, as the interview group did not include NMSC patients, it may not be sensitive to issues related to this population.[5] There are recent PRO instruments but were not designed to assess issues specific to facial areas.[6,7]

To appropriately measure the impact of facial procedures for skin cancer, clinically meaningful and psychometrically sound PRO instruments are needed. Developing a PRO instrument typically involves a literature review, patient interviews and expert opinion.[8] These three sources provide a comprehensive understanding of the important patient issues and can inform the development of the scales and items needed to measure patients' concerns. In this study, a qualitative approach was used to identify aesthetic and health concerns to develop a conceptual framework for a new condition-specific PRO instrument for patients undergoing facial skin cancer surgery.

Methods

Ethics board approval was obtained from the Institutional Review Board at Memorial Sloan Kettering Cancer Center. A pool of eligible participants was identified from the institutional database in Dermatology. Purposive sampling was used to ensure a heterogeneous sample of facial anatomic locations. Inclusion and exclusion criteria are seen in Appendix 1. Participants were recruited by mail or in clinic. Participants who agreed were contacted by phone to schedule an interview. Participants completed written consent forms and provided verbal consent at the start of the interview. Participants were free to withdraw at anytime.

In-depth semi-structured interviews were conducted by experienced qualitative researchers using an interview guide (Appendix 2). The interviews were recorded digitally and transcribed verbatim without participant identifiers. The interviews were conducted until data saturation (no new themes identified) was achieved. Data collection and analysis took place concurrently which allowed the interview guide to be modified as data was gathered. Each transcript was read carefully to gain an overview of the main issues important to the participants. Transcripts were then examined in detail to identify basic patterns and recurrent themes using line-by-line coding to examine, compare and develop conceptual categories using the constant comparison method.[9]

Results

Forty patients were invited to participate and 23 patients agreed to participate, 8 declined and 9 did not respond to the mailing. Due to scheduling conflicts or inability to come into the office, only 15 presented for the interview. The characteristics of the 15 participants are shown in Table 1. The skin cancer removal was performed by the dermatologic surgeon and the surgical closure performed by either the dermatologic (33%) or plastic surgeon (66%).

Analysis of the interview data revealed five main themes: appearance-related, psychological function, social function, adverse problems and experience of care. Sample patient quotes are seen in Appendix 3.

Appearance-related concerns

In general, participants felt their face looked natural after surgery and their appearance was not substantially altered. Participants were more satisfied if the scar was small and away from the central face. The scar texture, firmness and the color were comments even years after surgery. A few expressed that whether the scar was visible to others and in photos was important.

Psychological function

Worry and anxiety was commonly reported at the time of diagnosis due to uncertainty about the prognosis and of having "cancer." The worry mitigated for most after treatment. However, younger participants expressed more worry of new skin cancers developing. Overall, participants were not worried of getting other types of cancers. A few participants treated for melanoma reported thinking about their skin cancer almost every day.

Most participants reported not wanting to be seen by others if their scar was noticeable. Having a visible scar affected their desire to socialize and attend work. In the early post-operative period (<1 month), most participants felt self-conscious about their appearance. The social anxiety and self-consciousness were transient but included hiding their face and wearing sunglasses indoor.

Social function

During the post-operative period, participants were limited in their physical activities and attending work. Some avoided friends and family and had little interest in doing things. Wearing a bandage drew attention to the face and was associated with embarrassment. There were varying degrees of isolation depending on the participant's age, occupation and support network. Younger individuals were more likely to avoid work and socialization. One participant reported not feeling prepared for the changes in her appearance and avoided going out altogether.

For most participants, having a skin cancer led to modifications in social activities. For example, participants discussed how they changed their pursuit of outdoor activities, vacations and exposure to the sun. The majority of participants reported that their cancer experience led to greater sunscreen use and wearing clothing and hats to protect their skin when outdoors. The diagnosis of a skin cancer also prompted greater awareness of the participant's overall skin health. Many reported they now encouraged friends and family members to wear sunscreen.

Adverse problems

There was no long term sequela of facial function identified. Impediments in eating and smiling were in the early post-operative period due to swelling, bandages or pain. One participant had a drooping eyelid that was revised surgically.

When participants recalled the first week after surgery, pain was reported as being more than expected. Most described feeling their skin stretched, numb and swollen; for some this persisted for weeks. Bruising was significant enough to warrant avoiding social situations. During the recovery period, a few participants also commented on the wound care as being a nuisance.

Participants commented on abnormal sensations of the scar such as tingling, soreness, tightness or general sensitivity, which persisted for weeks to months. A few commented that the area took longer to heal than expected; unusual runny nose was also reported by one participant.

Experience of care

Satisfaction with the experience of care was important to the participant's overall view of their surgery. Participants reported anxiety was diminished by their confidence in the surgeon. When participants reflected on their experience, feeling well taken care and having concerns addressed were important. One patient commented on the phone delivery of bad news by non-medical professionals and feeling rushed on the phone were negative associations she experienced with the office that performed her initial skin biopsy.

Discussion

All participants prioritized the removal of the skin cancer over the aesthetic outcome. Most participants were pleased with the appearance of their scar; however, this was dependent on when they were interviewed in relation to the surgery. Having a noticeable scar was reported to be a source of distress. Participants experienced anxiety and social isolation in the early post-operative period when there was an inconspicuous bandage or swelling. The need to conceal the area also made participants self-conscious. Although facial scars can have a negative effect on self-esteem and confidence, existing scar scales do not comprehensively assess for psychological and social effects.[10,11]

Adverse effects have not been captured by existing PRO instruments for the skin cancer population.[4,12] Although the rate of traditional adverse events (e.g. infection) are low in dermatologic surgery, when patients were asked to comment on problems and complications, a broader range of concerns were elicited.[13] As clinicians may miss or underestimate adverse events experienced by patients, it is important to have tools to identify and measure these outcomes. A previous study that elicited quality of life issues did not report on adverse sequelae that was important to patients interviewed in this study.[3] The participant's experience with the surgeon and staff also had a positive influence on how they felt about their care. Evaluating patient satisfaction with health services is also relevant as this influences compliance, patient involvement and continuity of care.[14] With the growing emphasis on patient-centered care, clinicians will increasingly be scrutinized on the “value” of health care delivery and comprehensive methods of evaluating health care are needed.

There are limitations to this study. As the interviews were conducted at only one institution, the results may not be applied to the general skin cancer population. The location in a metropolitan city may suggest the observations are not reflective of the general population;

however, the interviewers obtained rich qualitative data that identified important themes and a wide spectrum of patients were identified for the interviews. Although only 15 interviews were conducted, additional themes were not identified. There are patients who undergo extensive facial resections with subsequent functional deficiencies; however, this population was not targeted as our research team previously reported on this population.[15]

The themes identified in this study provide a framework for a new PRO instrument: the FACE-Q Skin Cancer Module. Existing instruments address the broad concerns of the population, whereas this instrument will be innovative as it will comprehensively quantify the impact of a facial skin cancer on outcomes from scarring to adverse effects of treatment and the process of care. The instrument will consist of independent functionally scales encompassing the themes identified in this paper. The opportunity to measure outcomes specific to the facial skin cancer population from scarring, adverse effects of treatment to the health care experience is unique and may provide opportunities to better understand outcomes of skin cancer surgery patients. Information provided by a condition-specific PRO instrument will better convey expected outcomes, facilitate shared-decision making and improve the physician's ability to accurately communicate the expected outcomes of treatment.

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Appendix 1: Inclusion and exclusion criteria for participants being interviewed

Inclusion criteria	***Exclusion criteria***
Age 18-80 years	Inability to participate in interview due to a cognitive or sensory impairment
Surgical reconstruction with linear closures, skin grafts and local skin flaps	
Follow-up from 1wk to 5 years from surgery	
Ability to speak English and participate in interview	

Appendix 2: Interview guide for the qualitative interviews

Background questions: first skin cancer, number of skin cancers, skin cancer symptoms, treatments
Experience with care: feeling prepared prior to surgery, information about the surgery, repair options, expectations of procedure and recovery, satisfaction with information and surgeons
Facial appearance: changes in appearance, feeling about appearance, satisfaction with appearance
Facial function: effects of surgery on facial function
Social functioning: effects on daily activities, work, interference with outdoor activities, social gatherings
Emotional functioning: changes in confidence, distress from surgery/scar, cancer worry, future risk worry

Peri- and post-op symptoms: pain; discomfort, itchiness, tightness around scar, complications
Expectations: feelings before and after surgery, willingness to repeat; satisfaction with procedure

Appendix 3: Sample concepts and patient quotes

Theme/concept	**Example quote**
Perspective on diagnosis	It's serious and there are lots of gates that you have to get through to hopefully have a good result, but it's not the primary thing. (Female, 57 years, melanoma)
Surprise/shock	I was not expecting that [diagnosis]. I was pretty floored. I definitely am extremely concerned. I think that it's very easy to miss. The only reason that I caught that one was because it was staring me in the face when I looked in the mirror.” (Female, 27 years, BCC)
General scar appearance	When I look in the mirror, I see it (the scar). I feel like I almost have to explain it and I'd love just not have to do that.” (Female, 57 years, BCC)
Self-consciousness	I've been walking around with a bandage on my face, I've been wearing sunglasses. I feel odd; I feel like people are staring at it. I've been wearing sunglasses indoors which I don't do.” (Male, 39 years, BCC)
Insecurity	I told my husband put sheets or something on every mirror in the house; I don't want to look. And that worked good for me. (Female, 75 years, melanoma)
Scar color	You know, I know I've got a spot on my nose. Doesn't match in color, and when my blood pressure goes up, it matches less in color. (Female, 82 years, melanoma)
New perspective	Everything is outdoors so summertime you just have to limit it. I've looked at the sun differently, like it's not an invitation to go out.” (Male, 39 years, BCC)
Change in behavior	This nose thing has changed my whole perspective. I now wear hats. I have skin block in my car. I have skin block right on my basin in the bathroom and I make sure I wear it all the time.(Male, 58 years, SCC)
Social limitations	I couldn't work at that time. I lost a lot of time. It was just so bad. I run my own business. You can't afford to take a whole month off. No income is no income.” (Female, 58 years, BCC)
Functional limitations	You know my eye was – like the bottom lid was kind of drooping down and what else was there. Eating was very difficult.” (Female, 75 years, melanoma)
Wound care/dressings	I think it's the recovering from the surgery in terms of my silly allergies to the bandages and stuff, because that's just a royal pain.” (Male, 58 years, SCC)
Staff experience	The backup from the nursing staff is instrumental in making people happy.” (Male, 81 years, BCC).

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Table 1
Clinical characteristics of interviewed participants

	N (%)
Gender	
Male	6 (40)
Female	9 (60)
Age	
Mean (years)	58.2
20-40 years	3
40-60 years	5
60-80 years	7
Marital status	
Married	11
Single	4
Diagnosis	
BCC	6 ([*]1)
SCC	2 ([**])
Melanoma	6 ([***]3)
Other (MAC microcystic adnexal carcinoma)	1
Facial location	
Cheek	5
Nose	5
Forehead	3
Lip/eyelid	2
Procedure	
Mohs surgery	10
Wide excision	5
Reconstruction	
Primary repair	5
Flap repair	8
Full thickness skin graft	2 (1 also with flap repair)
Interview time from surgery	
< 6months	4
>6 months - 2 year	9
>2 year	2

[*] =also with history of melanoma

[**] =also with history of BCC

*** = history of BCC/SCC