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Physician Centered Outcomes for Skin Cancer Treatment; A Single Day Modified Delphi Process to Assess the Importance of Themes in Skin Cancer Management

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Abstract

Background: Success in skin cancer treatment is determined through outcomes measurement. Patients and physicians may prioritize different outcomes of care and identification of such may enhance patient-centered care.

Objective: To identify gaps between patient and physician attitudes towards skin cancer outcomes.

Methods and Materials: A single-day, 21-patient, modified, in person, Delphi process to solicit and rate the importance of skin cancer-related outcomes was conducted. Twelve blinded dermatologic surgeons rated patient generated outcomes in a two-round modified Delphi process. Each item was rated on a 1–9 scale (1- least important, 9 - most important) using the Qualtrics® web platform (Qualtrics, Provo, UT). Results of the physician ratings were compared to the patient ratings.

Results: A list of 53 skin cancer treatment related themes and outcomes was generated. Eight items were ranked by physicians as “very high” (>80% importance), 5 as “high” (>70%), 19 as intermediate, and 21 as low. The physician and patient panels’ ratings were concordant for 56% of items, while 7 outcome items showed a 2-category discordance.

Conclusion: Physicians and patients were concordant regarding skin cancer treatment on multiple spheres. Areas of discordance include: patient fear of unknown future risk, recurrence, or empowering patients to make treatment choices may be areas of continued improvement for delivery of patient centered care.

Keywords

Patient centered outcomes; Physician centered outcomes; modified Delphi method, skin cancer

Introduction:

Skin cancer is the most common form of cancer in the United States, affecting 4.9 million Americans.¹ Traditional cancer outcomes such as mortality, recurrence, and adverse events are sometimes used to determine the success of care in skin cancer patients. However, these conventional metrics measure uncommon events. In recent years, patient-centered outcomes have become increasingly important to clinical practice^{2–4} and to improve healthcare delivery and patient-focused care.^{5,6} These outcomes encompass the overall wellness of the patient and include elements such as physical, emotional, and psychosocial well-being.^{7–10}

Patient determination of healthcare delivery success is heavily influenced by expectations in care and perceived outcomes. Discrepancies in expectations and perceived outcome are known to reduce satisfaction across multiple aspects of healthcare.^{11–15} Similarly, discrepancies between patient and provider expectations can impair the perception of surgical outcomes.¹⁶ Aligning patient and provider expectations and perceived outcomes may help improve care^{17–20}. To date, there has been limited research on how skin cancer patients and physicians prioritize the currently available skin cancer outcome measures^{21–24}.

Identifying outcomes that are most relevant to skin cancer patients has come in the form of Rasch analysis and instrument^{25,26}. The Rasch analysis is a well know method of psychometric analysis for constructing surveys. However, physician input has little influence in the creation of these patient reported outcome measures. In order to better understand the patient and physician perspectives in skin cancer care, the American Society for Dermatologic Surgery Association (ASDSA) convened a patient-centered outcome summit to find a consensus on care from skin cancer patients and physicians using the modified Delphi method of structured communication. As part of that process we sought to explore gaps between patient- and physician-perceived importance of the patient outcomes.

Methods:

The study was approved by the Saint Louis University Institutional Review Board. Twenty-one patients were recruited through electronic correspondence by partner organizations (American Cancer Society, PIPC, and American Society for Dermatologic Surgery) as well

as direct recruitment of patients by the steering committee (IM, AR, JB, CB, TC, NL, MA) based on their perceived suitability for an in person, modified Delphi process. Patient attendees participated in a single day modified Delphi process to solicit and rate the importance of skin cancer related outcomes. The patient group generated and rated a list of 53 skin cancer treatment related themes and outcomes. The 53 outcomes were generated from solicited patient discussions by the patient panel at the outcomes meeting. Physicians on the steering committee who attended the consensus conference were blinded to the final results. In order to identify gaps between patient and physician attitudes towards skin cancer outcomes a physician portion of the modified Delphi was planned. Five additional physicians, expert in the treatment of skin cancer, were recruited to participate in the modified Delphi portion to achieve gender and career level balance in the physician cohort (MB, RB, MM, KN, JS). The 12-member physician panel was asked to rate each of the patient generated outcomes in a two-round modified Delphi process. Each item was rated on a 1–9 scale (1 being least important, 9 being most important) using the Qualtrics® web platform (Qualtrics, Provo, UT). After completion of the first rating round, all participants were able to view the anonymous input of the rest of the group before re-rating each item. Items with 80% of respondents rating the item as 7–9 were categorized as “very highly important.” Items rated 7–9 by more than 70% of respondents were categorized as high importance. Items rated 1–3 by 30% or more of respondents were categorized as “low importance”. Items not meeting any of the above three relevance cutoffs were considered to be of “intermediate importance.” These relevance cutoffs were pre-determined using accepted methods from psychometric analysis literature. Results of the physician ratings were compared to the patient ratings to identify any discrepancies.

Results:

All 12 physician panelists participated in both rounds of the modified, in person, Delphi. Physician panel demographics can be seen in Table 1. All physicians were dermatologic surgeons that worked at academic institutions across the United States and treated skin cancer patients regularly. There were 6 males and 6 females. Eight items were ranked by physicians as “very high” (>80%) importance, 5 as “high” (>70% importance), 19 as intermediate, and 21 as low. The physician and patient panels’ ratings were concordant for 56% of items (Table 2). There were 18 items that were ranked higher by patients than physicians (Table 3) and conversely 5 items that were rated lower in importance by patients compared to physicians (Table 4). Items with the greatest discrepancy in rating categorization are highlighted in Table 5.

Discussion:

Patient centered research is continuing to increase as the patient’s perspective is becoming more integrated in treatment decisions. The shift from a physician / disease specific point of view to a patient orientated one has created a new set of qualitative outcomes. This is true in cancer treatments of all forms and there is a paucity of such in regard to skin cancer. The patient-physician dichotomy can become evident in terms of outcome measures and care goals. Therefore, it behooves both parties to understand each other’s goals and concerns in

an effort to direct care and allocate resources. These may or may not align and it is important the physician be cognizant of these differences and similarities.

The ASDSA in association with PCORI, who sponsors patient-centered comparative clinical effectiveness research, conducted this in-person two-step modified Delphi consensus process that generated both patient rated and physician rated outcomes for cutaneous cancer. We previously reported on the outcomes that were considered important and relevant by this patient cohort (manuscript currently submitted for publication). We now report on those outcomes deemed relevant by participating physicians and compare that to patient outcomes to understand gaps that exist between physicians and patients in regards to skin cancer treatment.

The physicians were concordant with patients on majority of fields and therefore the physicians were well aligned towards patient priorities in respect to skin cancer treatment. The outcomes that had a “very high” (greater than 80%) concordance between physicians included: “severity of scar,” “being informed of the treatment options,” “confidence in physician’s ability,” “being heard by my physician,” “ability to return to normal activities,” “open communication with my physician.” The concordant outcome of scar severity shows that patients and physicians both consider the cosmetic long-term results of skin cancer surgery quite important as much or even more so than the efficacy or success of the procedure. This has been supported in recent literature exploring the psychosocial effects of scarring after skin cancer surgery^{27,28}.

The outcomes that had a “high” (greater than 70%) concordance between both patients and physicians included: “loss of capabilities to do my work (or job required change);” “feeling fully educated about your condition,” “empowered to ask questions,” and “feeling respected.” These other concordant outcomes also highlight the emotional and functional domains that encompass skin cancer treatment. The concordant items all imply that there are a range of issues in both the short-term post treatment range and the long term, follow-up period, that are of concern to both cohorts. Both physicians and patients want to establish open communication lines addressing both patient and physician concerns in regard to these short and long term goals.

The items that were most discordant between the patient and physician also shed important light on the gaps that can be targeted for improvement. These included: “fear of unknown future risk of recurrence (another skin cancer),” “fear of recurrence of primary cancer,” “proactive outreach from physician’s office (e.g. encouraging treatment),” “feeling empowered to make my own choices (for treatment),” “access to reliable information resources, specific to your condition.” These results emphasize the importance of continued care beyond the immediate surgery and continued education that should take place. This patient cohort expressed concern about future skin cancers and recurrence of the primary tumor and therefore continuity of care and a plan for future care / preventive care may assuage those concerns. These discordant items highlight a knowledge gap that may exist with patients that physicians may not proactively address.

These highlighted physician and patient perspectives have clinical implications in regard to patient compliance with the treatment protocol as well as overall patient satisfaction with the treatment.

Limitations:

The limitations of this study include the modest sample size and time limitations for sampling as this was done over a one-day period with physicians and patients. The physician cohort specifically was limited to academic dermatologic surgeons, which may skew concerns.

Conclusion:

Patient reported outcomes are essential to making effective treatment goals. This is one of the first studies to compare the physician and patient assessments of outcomes which are vital to a shared decision. The concordant themes are broad and span many spheres of care, while the discordant themes highlight the practice/knowledge gap that physicians may want to address. While it is not always possible to touch upon each item generated in this study during the initial patient / physician encounter it may be helpful to provide additional resources for patient education. This allows the patient to actively engage in the decision-making process and can then follow up with the physician regarding specific concerns. Communication, decision making, and physician patient relationship are all very important to skin cancer patients as shown in this study. Continued emphasis from physicians regarding shared decision making with patients is paramount to the delivery of patient centered care.

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Abbreviations:

ASDS American Society for Dermatologic Surgery

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Table 1:

Physician and patient panel demographics

	Physician panel demographics
Gender	Male = 6, Female = 6
Age	<40 = 50%, 40–49 = 41.6%, >50 = 8.4%
Academic Rank	Assistant = 50%, Associate = 25%, Professor = 25%
Ethnicity	Caucasian = 75%, Asian/Indian = 25%
Demographic Data for 21 patient modified Delphi participants.	
Gender	Male = 6; Female = 15
	Melanoma only = 7
	Melanoma and NMSC = 4
Tumor Type	NMSC oonly = 10
	> 30 = 1
	31–50 = 2
	50–70 = 13
Age at participation in years	>70 = 5
	IL = 6
	PA = 2
	MI = 2
	NJ = 1
	KS = 1
	NY = 1
	MN = 1
	MO = 1
	DC = 1
States of residence	AL = 1

Table 2:

Patient generated treatment related outcomes and themes that were rated concordantly by the physician and patient panels. The physician panel's consensus relevance consensus was concordant with that of the patient panel for the majority of items.

Fields rated concordantly by physician and patient panels	Rating
Confidence in physician's ability	Very High
Being heard by my physician	Very High
Able to return to normal activities	Very High
Open communication with my physician	Very High
Anxiety about the procedure	Intermediate
Pain	Intermediate
Amount of time to full recovery	Intermediate
Ability to pay for treatment	Intermediate
Amount of time away from usual activities required for treatment	Intermediate
Coordination of care with other health care providers (e.g., primary care physician, general dermatologist)	Intermediate
How you're affected by other people's reaction to way you look	Intermediate
Longer time to heal than expected	Intermediate
Giving up or changing important activities to me (e.g., sports)	Intermediate
Ease of navigating the health system to obtain care	Intermediate
Fear of judgment	Low
Connected to others spiritually	Low
Denial about ongoing, chronic nature of condition	Low
Feeling alone	Low
Depression	Low
Strained or lost friendships	Low
Anger	Low

Table 3:

Items rated more highly by the patient panel than by the physician panel

Items rated higher by the patients than the physicians	Patient rating	Physician rating
Gratitude for outcome	Very high	Low
Fear of unknown future risk of recurrence (another skin cancer)	Very high	Low
Fear of recurrence	Very high	Intermediate
Proactive outreach from physician's office (e.g. encouraging treatment)	Very high	Intermediate
Feeling empowered to make my own choices (for treatment)	Very high	Intermediate
Access to reliable information resources, specific to your condition	Very high	Intermediate
Acceptance of my health status	High	Intermediate
Feeling "used up" or exhausted from repeated treatment	Intermediate	Low
Accepting the "new normal"	Intermediate	Low
Responsible for encouraging others to get skin checked	Intermediate	Low
Linkage to resources for psycho-social support	Intermediate	Low
Emotional roller-coaster (or wide swing in emotions)	Intermediate	Low
Ignorance of what treatment may cost me	Intermediate	Low
Fear of incidental finding	Intermediate	Low
Pass along genes or skin cancer risk to children/family	Intermediate	Low
Change in lifestyle	Intermediate	Low
Anxiety about next tumor (in different location) – "never really a survivor"	Intermediate	Low
Bumps and bleeding of the affected skin area	Intermediate	Low

Table 4:

Items rated as less important by the patient panel than the by the physician panel.

Items rated lower by patients than physicians	Patient rating	Physician rating
See self as disfigured	High	Very high
Others see me as disfigured	Intermediate	Very high
Impact on relationships with friends and family	Low	Intermediate
Social withdrawal	Low	Intermediate
Ability to be a spouse or parent	Low	Intermediate

Table 5:

Items with a 2 or more-importance category discrepancy between patient and physician panel rating.

Items with greatest discrepancy between patient and physician rated importance	Patient rating	Physician rating
Gratitude for outcome	Very high	Low
Fear of unknown future risk of recurrence (another skin cancer)	Very high	Low
Fear of recurrence of primary cancer	Very high	Intermediate
Proactive outreach from physician's office (e.g. encouraging treatment)	Very high	Intermediate
Feeling empowered to make my own choices (for treatment)	Very high	Intermediate
Access to reliable information resources, specific to your condition	Very high	Intermediate
Others see me as disfigured	Intermediate	Very high