

Extraoral maxillofacial prosthetic rehabilitation at the M. D. Anderson Cancer Center: A survey of patient attitudes and opinions

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Statement of problem. Measures of satisfaction after extraoral maxillofacial prosthetic rehabilitation have been sparsely reported.

Purpose. This article reviews the care-related opinions of patients who were provided extraoral prostheses at the M. D. Anderson Cancer Center over the course of 10 years.

Material and methods. A questionnaire was delivered to 263 extraoral prosthetic patients to elucidate their degree of satisfaction with several parameters, including prosthetic use, care, quality, durability, longevity, and cost. In addition, issues relating to self-image, socialization frequency, and income-earning ability before and after rehabilitation were surveyed.

Results. The views of 76 respondents demonstrated a general satisfaction with their prostheses. A majority believed that their prostheses fit comfortably, and most were satisfied with cosmesis. In addition, a preponderance of respondents reported no substantial alteration in social activity after rehabilitation. Although the number of respondents relying on their own employment fell by more than 50% after rehabilitation, nearly all reported a relatively static income before and after rehabilitation.

Conclusion. The survey revealed a high degree of patient satisfaction with extraoral maxillofacial prostheses. Nevertheless, areas of potential improvement were not lost on the survey's population. The patients desired prostheses that last longer and have improved color stability. An interest in improved retentive mechanisms was mentioned by several patients, and only about half of the respondents perceived prosthetic cost to be completely reasonable. (J Prosthet Dent 2001;85:608-13.)

CLINICAL IMPLICATIONS

This complimentary patient review identified concerns with prosthetic longevity, color stability, and adhesion that could be mitigated through continued material science research, particularly in the areas of polymer chemistry, pigmentation, and implantology.

The psychologic, social, and economic challenges faced by maxillofacial prosthetic patients range from a fear of social rejection to the stark economic burden of losing employment or even one's life.¹⁻⁴ Although these struggles often manifest as clinical depression, no simple correlation between the volumetric expanse of maxillofacial defects and depressive severity has been observed.^{1,5} However, the extent of depression has been linked to defect cause, in that patients encountering a neoplastic diagnosis are prone to more exaggerated bouts of depression than are those whose maxillofacial prosthetic therapy is necessitated by congenital or traumatic deficits.⁶

An overall improvement in the psychologic profile

of patients after maxillofacial prosthetic rehabilitation has been shown.^{5,7} Although objective and subjective evaluations by the therapeutic team and the patient, respectively, may be divergent,⁵⁻⁶ a relative measure of treatment success may be assumed when patients comfortably use their prostheses. Prosthetic usage is in turn related to the appropriate manipulation of befitting materials to realize cosmesis, retention, durability, and tissue compatibility.⁸⁻⁹

In the interest of quality assurance in the Department of Head and Neck Surgery's Section of Oncologic Dentistry and Prosthodontics at the University of Texas M. D. Anderson Cancer Center (MDA), an assessment of patient attitudes regarding facial prosthetic rehabilitation was undertaken. Although not a novel proposition,^{6,10-12} a new patient opinion survey is relevant in light of evolving materials and methodology. The purpose of this article is to review patient responses to a survey on satisfaction with and the use of facial prostheses constructed at the MDA.

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MATERIAL AND METHODS

A 10-page, 52-question survey was written by a prosthodontist and reviewed by a psychologist to ensure comprehension by an individual possessing the equivalent of a sixth grade education. The target population included patients treated with facial prostheses at the MDA during the previous 10 years.

The survey inquired of demographic information such as age, gender, race, prosthetic type, and duration of time since cancer surgery (if surgery had been performed). It also probed issues relating to prosthetic use, care, quality, durability, and longevity. The patients were queried regarding the necessity for assistance with prosthetic care and positioning from a second party as well as the informational quality of the MDA staff's instructions. Perceptions of self-image were explored by asking whether patients believed friends or strangers noticed the existence of their prostheses or whether they would allow friends or relatives to visualize them without their restorations. Similarly, patients were asked whether they felt self-conscious about going to certain places without their prostheses.

Other questions delved into socialization frequency before and after prosthetic rehabilitation. An effort was made to determine the population's conception of the fairness of their prosthetic fee, and several questions dealt with the issue of patients' fiscal status before and after rehabilitation. Finally, open-ended questions were presented concerning the general opinion patients had of their prostheses and what they might do to change their prostheses if they were given that option.

RESULTS

Of the 263 mailed questionnaires, 76 were returned. Relatives identified 16 deceased patients, and 25 surveys were returned as undeliverable. Fifty-two (68%) respondents were men, 23 (30%) were women, and 1 respondent failed to disclose a gender. Ages ranged from 35 to 93 years, with an average of 66.9 years. Sixty-seven (88%) subjects were white, 4 (5%) were African American, and 3 (4%) were Hispanic; 2 subjects failed to reveal their race. Three (4%) respondents reported no neoplastic disease history, whereas 73 (96%) had had an ablative cancer surgery. Survival intervals since surgery ranged from 13 months to 45 years. The mean duration of time since surgery was 8.99 years.

The nasal prosthesis was encountered most frequently. Twenty-seven (36%) patients possessed prosthetic noses. Fourteen (18%) patients had orbital or ocular prostheses, and 12 (16%) were provided auricular prostheses. Fourteen (18%) patients used combination prostheses incorporating a maxillary denture, whereas 2 patients (3%) possessed orbital prostheses combined with nasal or cheek components.

One respondent used a prosthetic toe, 3 mentioned only a denture, and 2 gave imprecise answers to the question asking what type of prosthesis had been fabricated. Sixty (79%) respondents reported routine use of their prostheses; 11 (14%) did not.

Fifty-nine (78%) respondents answered affirmatively when asked whether they wore their prostheses at home; 15 (20%) replied negatively. Thirty-seven (73%) of 51 employed patients said that they wore their prostheses to their workplace. When queried whether prostheses were being worn to social gatherings, 64 (84%) said yes and 9 (12%) said no. Fifty-three (70%) respondents reported not wearing and 20 (26%) reporting wearing their prostheses during sleep. The average daily use of prostheses was 14.34 hours; however, 18 (24%) respondents said that they wore their prostheses 24 hours a day.

Forty-three (57%) patients reported that their prostheses had been remade at least once, whereas 30 (39%) were using original prostheses. Twenty (63%) of 32 respondents possessing succedent prostheses mentioned "wear" or "tear" as being fully or partially responsible for their desire for new prostheses. A change in "fit" or "color" motivated 7 (22%) others to seek new prostheses. One patient found having duplicate prostheses to be a convenience, whereas 3 patients either lost or could not tolerate their original prostheses. Another person stated that his first prosthesis was made with an interim intent, and 1 person said his prosthesis was replaced in the interest of science. The average of a sampling of responses to the question of how long prostheses lasted before having to be replaced was 2.24 years; the average age of the collective prostheses being used by the population was 3.98 years. The most aged prosthesis in use was 30 years old, and the newest was 2 weeks old.

With regard to hygienic habits, 41 (56%) patients reported cleaning their prostheses daily. The average cleaning frequency for the entire group was 2.28 days. The most fastidious groomer cleansed his prosthesis 4 times a day, whereas the most lax reported a monthly cleaning frequency. Water only was used as a cleansing medium by 25 (33%) of the respondents; 17 (22%) combined soap and water as their agent of choice. Seven (9%) patients used a solvent to clean their prostheses, and 6 (8%) used alcohol. Two of those who used some kind of solvent specifically identified one of the Factor II products. Five (7%) patients used several combinations of salt, bleach, alcohol, solvent, or soap with water to clean their prostheses. One patient reported the use of Efferdent to clean a combination orbital and denture prosthesis, and another used toothpaste to clean an acrylic resin nasal prosthesis.

Another inquiry measured the difficulty of cleaning prostheses (Table I). Patients responded to a statement using a 5-point scale, with "1" representing the most

Table I. Patient responses to questions about prosthesis care, fit, comfort, durability, appearance, and cost

Statement	Rating					No answer
	1	2	3	4	5	
The prosthesis is easy to clean.	1 1%	5 7%	5 7%	32 42%	28 37%	5 7%
The prosthesis is comfortable.	3 4%	2 3%	5 7%	36 47%	29 38%	1 1%
The prosthesis feels good.	5 7%	4 5%	12 16%	32 42%	22 29%	1 1%
The prosthesis is soft enough.	3 4%	1 1%	4 5%	26 34%	29 38%	13 17%
The prosthesis is hard enough.	2 3%	0 0%	12 16%	22 29%	30 39%	10 13%
The prosthesis makes my skin sore.	27 36%	15 20%	6 8%	14 18%	4 5%	10 13%
The prosthesis has a good shape.	1 1%	4 5%	2 3%	33 43%	32 42%	4 5%
The prosthesis fits well.	2 3%	4 5%	3 4%	32 42%	29 38%	6 8%
The prosthesis margins have remained intact.	2 3%	6 8%	7 9%	28 37%	24 32%	9 12%
The doctors and nurses explained clearly how to care for my prosthesis.	1 1%	3 4%	4 5%	16 21%	49 64%	3 4%
The written instructions were easy to read and helpful. (Eight respondents reported not receiving written instructions.)	2 3%	2 3%	5 7%	11 14%	39 51%	9 12%
The prosthesis stays attached.	5 7%	3 4%	3 4%	41 54%	20 26%	4 5%
The prosthesis looks natural.	5 7%	2 3%	13 17%	32 42%	22 29%	2 3%
The prosthesis color is a good match.	2 3%	6 8%	1 1%	32 42%	29 38%	6 8%
Friends do not notice my prosthesis.	5 7%	10 13%	9 12%	27 36%	15 20%	10 13%
New acquaintances do not notice my prosthesis.	6 8%	10 13%	10 13%	21 28%	20 26%	9 12%
The prosthesis cost was reasonable.	1 1%	6 8%	18 24%	21 28%	19 25%	11 14%

Rating: 1 = completely disagree; 2 = mostly disagree; 3 = neither agree nor disagree; 4 = mostly agree; and 5 = completely agree.

negative or disagreeable response and “5” representing the most positive or agreeable response. An answer of “1” or “2” indicated that the patient “completely disagreed” or “mostly disagreed” with the statement presented, respectively. A reply of “3” was regarded as neutral, in that the patient “neither agreed nor disagreed” with the statement. Responses of “4” or “5” indicated that the patient “mostly agreed” or “completely agreed,” respectively.

Sixteen additional statements followed the aforementioned format (Table I). Several related to prosthetic comfort. A pair of dichotomous assertions elucidated thoughts regarding prosthetic material consistency. One statement related to prosthetic shape, 1 concerned prosthetic fit, and another addressed prosthetic marginal integrity. Two assertions respecting the

adequacy of the clinical staff’s written and oral home care instructions were revealing, as 8 respondents reported not receiving written directions.

One statement (Table I) and several questions addressed prosthetic adhesive security. Thirty-seven (49%) patients said that their prostheses had no liner, 17 (22%) said that their prostheses did, and 17 did not know whether their prostheses had liners. Sixty-two (82%) patients used an adhesive to assist in retaining their prostheses, whereas 9 (12%) did not. Thirty-three (53%) of those reporting the use of an adhesive used Epithane 3, 8 (13%) used Secure, and 10 (16%) used double-sided tape. Another 8 (13%) patients used combinations of these adhesives, and 1 purportedly used Fixodent to maintain the position of a combined denture and orbital prosthesis.

Table II. Prosthesis wear in public

Question	Yes	No	No answer
Would you allow someone to see you without your prosthesis?	42 55%	26 34%	8 11%
Is there any place you would not go without your prosthesis?	18 24%	50 65%	8 11%

Table III. Frequency of socialization at home

	Frequency before cancer diagnosis	Frequency after cancer diagnosis
Never	9 (12%)	10 (13%)
Once a month	14 (18%)	15 (19%)
2 to 5 times a month	20 (26%)	21 (28%)
More than 5 times a month	24 (32%)	21 (28%)
No answer	9 (12%)	9 (12%)

Prosthetic appearance, how patients are perceived by others, and how respondents feel about letting others see them without their prostheses were appraised through several statements (Table I) and questions (Table II). Although a majority believed their prostheses successfully matched the color of their skin, 40 (52%) respondents noted a detectable change in the color of their prostheses over time.

Whereas the number of patients who indicated that they would allow others to see them without their prostheses was limited to 42, 49 persons specified people with whom they would feel comfortable without their prostheses. Twenty-nine (59%) of these persons restricted this level of comfort to their immediate family; the remaining 20 (41%) included friends. Patients communicating a desire not to be in particular locales without their prostheses mentioned several venues that they would avoid. Ten said they would not go anywhere in public, whereas several persons referred to bed, the store, their church, and the swimming pool as places that they would eschew.

Forty-nine (64%) patients said that they take sole responsibility for the care of their prostheses; 21 (27%) allow others to assist them. The caregivers included 20 spouses, 1 child, and 1 nurse. Their care was provided "all of the time" in 13 instances, "most of the time" in 3 instances, "half of the time" in 2 instances, "sometimes" in 2 others, and "once in a while" in 1 circumstance. In an effort to establish how treatment affects social lives, 2 questions required an estimation of how many times per month patients' entertained guests at home before and after their diagnoses of cancer (Table III). The respondents were offered 4 ordinal choices from which to choose. They included "never," "once a month," "2 to 5 times a month," and "more than 5 times a month." A majority of the

Table IV. Sources of income before and after cancer diagnosis

	Before	After
Self-employment or wages	14 (18%)	6 (8%)
Spouse's paycheck	5 (7%)	2 (3%)
Private income (investments)	0 (0%)	1 (1%)
Social Security or Veterans' Administration	26 (34%)	36 (47%)
Combination of the above	23 (30%)	25 (33%)
No answer	8 (11%)	6 (8%)

patients reported that their socialization frequency after their diagnoses remained equivalent to that which existed before their illnesses. However, 10 (13%) respondents related a decreased social life, and 5 (7%) indicated an increased rate of social interaction.

Several questions investigated the possible alteration of the patients' fiscal status. The population was asked whether their incomes had fluctuated since they initiated cancer treatments, and an inquiry into their sources of income before and after their diagnoses was also made (Table IV). Although 33 (43%) respondents reported no change in their levels of income, 26 (34%) said their income had diminished. Only 11 (14%) patients' revenues increased.

A statement (Table I) and a question dealt with patients' satisfaction with the cost of their prostheses and the method by which they paid for their prostheses. Ten (13%) patients were solely responsible for the payment for their prostheses, 11 (14%) said Medicare paid their entire expense, 3 (4%) reported that the fees were collected from Medicaid, and 9 (12%) said that their insurance carriers satisfied the total debt. Four (5%) patients used "other" modes of reimbursement. Thirty-seven (49%) respondents mentioned combinations of these modes as a method of requital. Summarily, 21 (28%) respondents were covered at least partially by Medicare, 6 (8%) by Medicaid, and 34 (45%) by insurance. Only 27 (36%) patients used personal finances to partially or fully satisfy their obligations.

DISCUSSION

A male predilection for neoplastic disease in the head and neck region¹³ is possibly responsible for the survey's skew favoring male opinions. The importance of improving public awareness of potential damage generated from overexposure to solar radiation may be

implicit from the preponderant incidence of nasal prostheses. The fact that a majority of respondents comfortably wear their prostheses routinely could indicate patients' perceived value of the maxillofacial prosthetist. The disparity between the population's mean postoperative survival time and the average length of time the respondents' prostheses lasted underscores a need for continued efforts by polymer chemists and prosthodontists to improve in the arena of material science. Enhancement in material durability and color stability are especially needed, as a general satisfaction with prosthetic materials' comfort, consistency, fit, tone, and shape generally exists before remakes are necessitated by issues involving "wear and tear" and altered color and fit.

Despite clinical efforts to ensure that all patients were cognizant of the manner in which they should care for their prostheses, many responses regarding hygiene indicated a misunderstanding of the import of keeping prostheses meticulously clean. The lack of soap and water use, the use of inappropriate solvents, and infrequent cleansing hastens the deterioration of prosthetic polymers, especially at the periphery of the prostheses. This issue is particularly important when consideration is given to the fact that adhesives are used by a majority of patients. Marginal adhesive accumulation contributes to discolored and/or ill-fitting borders and peripheral deterioration. Although concerted efforts to review and provide written instructions could mitigate problems of this nature, ongoing advances in the use of maxillofacial osseointegration should also abate adhesive complications. In addition, the use of magnets incorporated into acrylic resin frameworks has proved to be an alternative or adjunctive method of securing prostheses in patients possessing defect undercuts conducive for mechanical retention. As with implant retention, these devices assist with the patients' ability to accurately position their prostheses in addition to decreasing or eliminating the need for adhesive.

The few respondents opposed to allowing others to see their exposed defects or refusing to be away from their homes without their prostheses may be indicative of a high level of patient confidence and/or a refreshing degree of empathy from friends, acquaintances, and even strangers. Conversely, this observation may be a function of the fact that a small majority of the patients believed that friends and acquaintances recognize their defects whether they are wearing their prostheses or not. Some patients have perchance forsaken the hope that they can completely disguise their imperfection. Likewise, unaltered socialization habits are possibly indicative of nonchalant patient attitudes regarding self-image. In addition, although twice as many patients reported a decreased level of socializing at home compared with those whose entertaining fre-

quency increased, those reporting any change in this frequency represented only 20% of the respondents. The social lives of the remaining patients were equivalent before and after their illnesses.

Although governmental policies exist to eliminate discrimination against workers with disfigurements, one would be naive to believe that such discrimination does not occur. Although patient incomes before and after maxillofacial rehabilitation might be representative of the overall success achieved from such efforts, the fiscal status of an elderly population of cancer patients may not serve as a reliable index of employability. Many cancer patients are forced into retirement not necessarily by their disfigurement, but by their therapeutic struggles, and many are retired before their diagnoses. It is important to keep this in mind when considering that more than 75% of this study's population reported either decreased or unchanged incomes after rehabilitation.

Although only 13% of the patients paid for their prostheses without third-party assistance, only 53% of the patients believed their prostheses' price was within reason. This observation is suggestive of a need by the profession to more effectively communicate the labor-intensive nature of its efforts. Patients perchance perceive the prosthesis as a piece of painted rubber despite their full appreciation of its rehabilitative value. Antithetically, prosthodontists may have difficulty discerning how a patient who has spent several hours at each of several clinical appointments could underestimate prosthetic cost. These conflicting opinions could be ameliorated with more intensive patient education with respect to the processes involved in the fabrication of maxillofacial prostheses. Also, the finding that only 36% of the patients were at all financially responsible for their care on a personal level signals the need for maxillofacial prosthetic and prosthodontic organizational groups' continued efforts to establish a rapport with all third-party payers, whether they be governmental or private.

Finally, a pair of open-ended questions reiterated much of what other queries in the survey addressed. That is, a majority of the respondents were satisfied and even thankful for the prosthetic services that they received at the MDA. However, even the most satisfactory rehabilitation can be improved. Responses to the question of what patients would change about their prostheses if given the opportunity corresponded with answers given earlier in the survey regarding motivations for remaking prostheses. The patients wanted their prostheses to last longer, wished for greater color stability, and were concerned about fit. Several patients mentioned a desire to eliminate the use of adhesives that they found awkward and irritating. Some auricular prosthetic patients suggested making their prostheses easier to properly position;

other suggestions related to anatomic proportional concerns. On the lighter side, 1 patient requested blinking eyelids in his orbital prosthesis.

SUMMARY

A questionnaire designed to collect information on patient attitudes about extraoral maxillofacial prosthetic rehabilitation was delivered to 263 former or current patients of MDA. Although responses from 76 patients revealed a high level of satisfaction with the quality of their care, the maxillofacial prosthetist should not be flattered into complacency. Suggestions for improvement were accompanied with responses from even the most gratified patients.

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