

Issues of importance reported by persons with lower limb amputations and prostheses

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Abstract--The purpose of this paper is to report prosthesis-related issues of importance that were identified by a diverse group of persons living with lower limb amputations (LLA) and prostheses. These perceptions and themes validate some old assumptions and challenge others, report both common and unusual experiences, and indirectly identify the information level of our respondents concerning prostheses. Persons with LLA were identified from computerized rosters at a level one regional trauma center and at the VA Puget Sound Health Care System-Seattle, Division. Inclusion criteria specified that respondents were to: 1) be one or more years post-unilateral amputation at the Syme's level (ankle disarticulation) or higher, 2) use their prosthesis at least 5 days a week, 3) read English, and 4) be able to provide informed consent. Respondents completed the Prosthesis Evaluation Questionnaire-field version (PEQ) and the standard form (SF)-36, a health status measure. Of 114 persons who agreed to participate, 92 (85% male, mean age 55 years) responded to the questionnaire and graded the personal importance of various characteristics and qualities of their prosthesis. The number of years since their last amputation ranged from 1 to 53 years. Four Themes of Interest were identified from responses to open-ended questions about living with a prosthesis. These themes included the fit of the socket with the residual limb, aspects of the mechanical functioning of the prosthesis, other nonmechanical qualities, and advice about adaptation to life with a prosthesis with support from others. Future research is recommended to adjust aspects of the fit of the prosthesis with the residual limb. Implementing periodic check-up visits could uncover problems and eliminate unnecessary

suffering.

Key words: *lower limb amputation, lower limb prosthesis, quality of life, rehabilitation.*

INTRODUCTION

Despite the presence of literature on the epidemiology of lower limb amputations, studies of the degree of mobility following lower limb amputation, and surveys of new amputees to learn who will use a prosthesis (1-6), there is little published information about issues of interest to persons functioning with a lower limb prosthesis. Without this information, it is difficult to make informed choices about a proper focus for patient-centered research in prosthetic rehabilitation. This paper describes aspects of living with a lower limb prosthesis about which persons with prostheses have expressed interest and concern. These ideas are presented to better inform clinical providers who must make decisions relating to amputation surgery and prosthetic prescription.

Each lower limb amputation (LLA) is a unique experience for the patient and the issues of loss and replacement have different meanings to each person. For all concerned, it is a paramount goal to secure a prosthesis that returns what is missing in a functional manner following the amputation. The purpose of this paper is to report prosthesis-related issues of importance identified by a diverse group of persons with lower limb amputations and prostheses. These perceptions validate some old assumptions, report both common and perhaps unique experiences, and indirectly identify the information level of our respondents about real and imagined limitations of prostheses. To assist in the generalization from our study findings, the health status scores of this group are compared with norms for the U.S. population.

METHOD

Study Sample

This descriptive study was conducted from March 1995 to June 1997. Persons with LLA were identified from computerized rosters of persons with amputations from a level one regional trauma center and from the Department of Veterans Affairs Puget Sound Health Care System, Seattle Division, in Seattle, WA. Inclusion criteria specified that respondents were to: 1) be one or more years post-unilateral amputation at the Syme's level (ankle disarticulation) or higher; 2) use their prosthesis at least 5 days a week; 3) read English; and 4) be able to provide informed consent for the study as approved by the University of Washington's Human Subjects Committee. One hundred forty-four individuals for whom current addresses could be ascertained were notified about the project by mail. They were telephoned to confirm eligibility and interest; 126 persons passed the eligibility screen. One hundred-fourteen of those who were eligible agreed to participate while 12 declined for reasons of health or time constraints. In all, 92 persons completed the consent form and questionnaire at home and returned the materials by mail.

Measures

Two instruments provided data for this report, the Prosthesis Evaluation Questionnaire (PEQ) developed by the authors (7) and the standard form (SF)-36 (8). The PEQ was developed using the conceptual model of "quality of life" (9) that suggests that multiple life domains are affected by health. In the case of LLAs, the questions covered major aspects of life that might be affected while living with a lower limb amputation and prosthesis (e.g., physical, psychological, and social). The PEQ was designed to allow a person living with a prosthesis to self-rate the qualities of the prosthesis from the perspective of the user, one's ability to perform various activities while using the prosthesis, and psychological and social effects of living with the prosthesis. The PEQ consisted of paired questions that asked the respondent first to rate his/her ability to perform an activity or to describe a characteristic of his/her prosthesis, and second to rate the personal importance of that activity or characteristic. Responses about the importance of each characteristic are reported in this article; the measures of ability to perform a function are reported elsewhere (7).

The following three open-ended questions were at the end of the PEQ:

1. What is the one thing you would NOT want changed about your prosthesis (because it is so good)?
2. What aspect of your prosthesis would you most like to have changed if it were possible?
3. What could you tell us about your life or prosthesis that might be helpful for the study team to know?

The responses to these questions formed the Themes section below.

The SF-36 is a standardized, multidimensional health status questionnaire (8). The resulting scores are grouped into eight subscales: physical function, role limitations-physical, vitality, general health perceptions, pain, social function, role limitations-emotional, and mental health. Each subscale is scored from zero to 100 (0=worst situation, 100=best situation). The SF-36 is not disease-specific; thus, scores can be compared for persons with and without any particular disease or impairment. This survey instrument has been used in a wide variety of clinical research studies and has demonstrated good reliability and validity. The SF-36 has been shown to discriminate between known groups, is reproducible, and is responsive to longitudinal clinical changes. U.S. population-based norms have been established for the eight subscale scores (10).

Data Management

The PEQ questions employed a linear analog format (0-100 cm) and scores were entered directly into a data management program using a digitizing tablet and a marking pen (11). The SF-36 employs Likert-like scoring that was entered by hand, and scoring was computed according to instructions from Ware and colleagues (10). The open-ended comments were recorded verbatim in an Excel database for review to identify themes. Statistical analysis was completed using SPSS for Windows (12).

Analysis

The demographic characteristics for respondents younger than 65 years of age were compared

with respondents 65 years old or older, using the Chi-square statistic to detect a difference in the distribution of the characteristics between age groups. A p-value of 0.05 or less was chosen to reflect statistical significance. Student's t-tests were used to compare U.S. population norms with our sample's mean SF-36 scores and to compare mean Importance scores from the PEQ among subgroups of the sample. The open-ended responses were reviewed for common themes and quotations were selected to exemplify these themes.

RESULTS

Description of the Sample.

Seventy-nine of the 92 study participants were male (85.9 percent). The mean age was 55 years, ranging from 22 to 81 years. Sixty-two percent of the respondents were married and 27.8 percent had diabetes. Nearly two-thirds of the respondents (62 percent) had undergone LLA more than 5 years ago, and nearly two-thirds of the amputations were transtibial (63.0 percent). **Table 1** illustrates the distribution of personal characteristics. No statistically significant differences were found in the distribution of these characteristics across age groups (<65, >64 years).

Table 1.

Demographic findings for respondents.

Characteristic (%)	Total n=92
Male	85.9
Married	62.0
Diabetes Mellitus	27.8
>5 years since LLA	62.0
Level of LLA:	25.0
Transfemoral	
Through the knee	3.3
Transtibial	63.0
Syme's ankle	8.7

We compared the self-reported health status of the respondents with U.S. population norms, using the eight subscales of the SF-36 (**Figure 1**). The mean scores of our total sample were significantly lower on all scores except on the mental health score ($p < 0.05$: physical function, physical role limitations, bodily pain, general health, vitality, social function, emotional role limitations). The age distribution of our male and female groups' were normal, and when male and female subscale scores were analyzed separately, the results were similar to those for the whole sample.

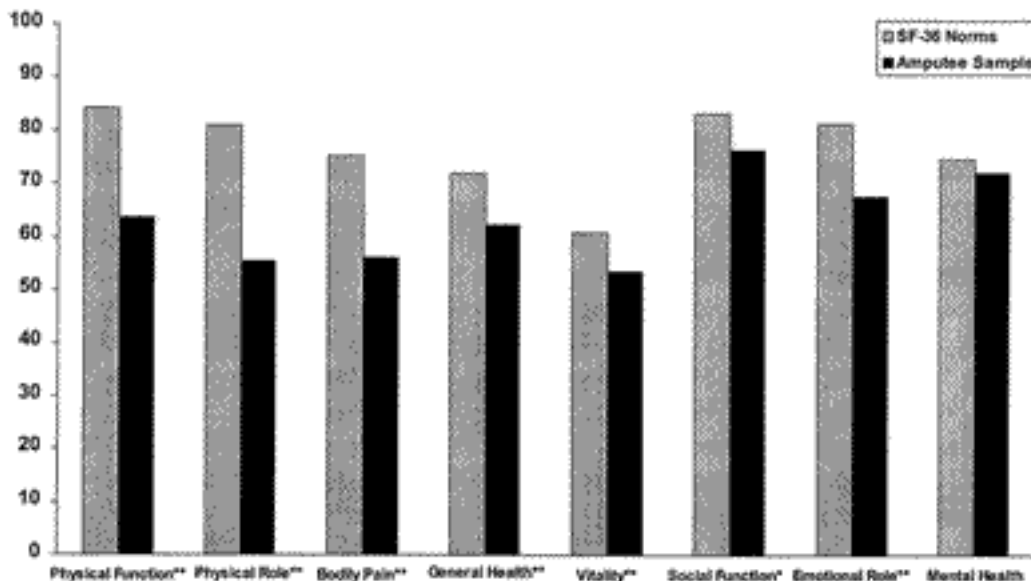


Figure 1.

SF-36 subscale scores: comparison of age comparable U.S. population norms (n=2,474 with the sample of persons with amputation (n=92); +p<0.05; *p<0.01; **p<0.001.

PEQ Importance Scores

The "Importance" questions were posed within seven categories. The first four categories address aspects of prosthetic function: Utility/Usefulness, Residual Limb Health, Appearance, and Sounds. The fifth group of questions, "Ambulation," rated the importance of prosthetic characteristics to one's mobility. The last two topics assess the importance of psychosocial issues "Perceived Response" and "Social Burden." Importance scores ranged from 60.8 to 98.1 (0=worst possible and 100=best possible). In **Table 2**, scores for each question are ranked by degree of importance. Patients rated the fit of the prosthesis (mean score=98.1), ability to walk with the prosthesis (97.6), avoidance of blisters or sores on the residual limb (96.7), and avoidance of rashes on the residual limb (95.2) as the most important factors associated with the use of a prosthesis. Items receiving the highest importance ratings also had the smallest standard deviations. Other items with high importance ratings (scores averaging from 90-95) included balance, comfort while standing, the ability to walk on sidewalks, and the ability to walk up and down stairs.

Table 2.

Correlations between prosthetic importance ratings and respondent characteristics.

Category	Mean (SD)	Differences				
		Age ¹	Sex ²	DM ³	LLA ⁴	Level ⁵

Importance Ratings

Utility

Fit of prosthesis	98.1 (4.1)	0.309	0.001⁶	0.893	0.161	0.610
Not feeling off balance while using prosthesis	94.6 (13.5)	0.119	0.004⁶	0.750	0.302	0.401
Comfort while standing when using prosthesis	93.0 (14.5)	0.150	0.001⁶	0.145	0.717	0.701
Ease of putting on prosthesis	89.4 (15.7)	0.250	0.720	0.406	0.171	0.432
Feeling and texture of prosthesis against residual limb	89.1 (19.3)	0.182	0.003⁶	0.635	0.024⁷	0.283
Comfort while sitting while using prosthesis	88.8 (17.6)	0.382	0.217	0.621	0.923	0.094
Prosthesis does not require a lot of energy for use	87.9 (20.9)	0.805	0.001⁶	0.729	0.178	0.054
Weight of prosthesis	85.7 (22.6)	0.490	0.729	0.614	0.979	0.751

Residual Limb Health

Avoidance of blisters or sores on residual limb	96.7 (11.0)	0.155	0.371	0.421	0.364	0.169
Avoidance of rashes on residual limb	95.2 (12.5)	0.266	0.307	0.482	0.242	0.176

Ability to keep prosthesis from smelling	85.4 (24.7)	0.941	0.000⁶	0.789	0.210	0.760
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Avoidance of ingrown hairs on residual limb	84.7 (28.7)	0.750	0.061	0.384	0.457	0.156
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Appearance

Prosthesis does not damage clothing	85.3 (19.6)	0.745	0.027⁶	0.582	0.776	0.963
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Cover of prosthesis is durable	75.2 (29.9)	0.336	0.030⁶	0.030⁸	0.595	0.033⁹
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Able to wear preferred shoe types	71.3 (29.2)	0.237	0.339	0.461	0.773	0.398
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Prosthesis does not limit choice of clothing	68.9 (33.9)	0.102	0.001⁶	0.502	0.522	0.293
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Appearance of prosthesis	60.8 (35.0)	0.732	0.000⁶	0.294	0.199	0.443
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Sounds

Prosthesis does not produce noise	83.0 (25.4)	0.438	0.003⁶	0.373	0.927	0.680
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Mobility

Ambulation

Ability to walk with prosthesis	97.6 (6.4)	0.518	0.002⁶	0.187	0.670	0.631
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Ability to walk on sidewalks and streets with prosthesis	92.5 (15.5)	0.264	0.861	0.290	0.235	0.500
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Ability to walk down stairs with prosthesis	91.0 (17.7)	0.158	0.668	0.254	0.638	0.310
Ability to walk up stairs with prosthesis	90.6 (17.0)	0.127	0.393	0.085	0.674	0.222
Ability to walk in close spaces	86.5 (25.4)	0.021¹⁰	0.598	0.303	0.563	0.689
Ability to walk on slippery surfaces with prosthesis	82.4 (29.5)	0.031¹⁰	0.454	0.148	0.154	0.161
Ability to walk down a steep hill	75.1 (29.3)	0.416	0.785	0.008⁸	0.270	0.875
Ability to walk up a steep hill	73.6 (31.5)	0.550	0.690	0.009⁸	0.366	0.504

Psycho-Social Issues

Perceived Response

Partner's acceptance of prosthesis	81.8 (30.8)	0.298	0.719	0.644	0.118	0.929
How a second family member accepts prosthesis*	73.6 (35.0)	0.780	0.333	0.434	0.342	0.998
How a family member accepts prosthesis*	71.3 (36.3)	0.658	0.700	0.676	0.219	0.577

Social Burden

Ability to take care of someone else	84.6 (26.9)	0.574	0.301	0.210	0.535	0.591
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Prosthesis is not a burden to partner or family	83.4 (28.8)	0.953	0.221	0.225	0.782	0.494
Having an active social life	76.8 (28.4)	0.532	0.291	0.820	0.437	0.375

¹Age: <65 vs. >65 years old; ²Sex: male vs. female; ³DM: diabetes mellitus vs. no diabetes; ⁴LLA: years since amputation, <5 vs. >5; ⁵Level: amputation level, transfemoral vs. transtibial: 11 participants with Syme's or trans-knee LLAs were not included in the analysis, thus n=81 for this subgroup with an age distribution of n=55 (<65) and n=26 (>65); ⁶**Females** had a significantly higher score in this category; ⁷**persons with 5 or fewer years since amputation** had a significantly higher score in this category; ⁸**persons without diabetes** had a significantly higher score in this category; ⁹**persons with transtibial amputation** had a significantly higher score in this category; ¹⁰**persons younger than 65** had a significantly higher score in this category; *The subject identified a family member other than his/her partner.

Items of moderate importance, scores averaging from 80-89, included aspects of Usefulness (Utility) of the prosthesis, such as the ability to put on the prosthesis (89.4 [15.7]) and the weight of the prosthesis (85.7 [22.6]). Other items that received moderate importance ratings included the ability to keep the prosthesis from smelling badly (85.4 [24.7]) and not producing noise (83.0 [25.4]).

Items receiving the lowest importance scores were appearance-related items such as the ability to wear preferred shoes (71.3 [29.2]), clothing limitations (68.9 [33.9]), and the appearance of the prosthesis (60.8 [35.0]). Items in the Perceived Response and Social Burden categories had lower importance ratings. The items regarding a family member's acceptance of the prosthesis (other than a partner or spouse) had scores in the low 70s. The ability to walk up and down steep hills (Ambulation category) also received low scores. Items with low importance scores tended to have higher standard deviations, indicating diverse opinions on the topics.

With the relatively few females in this study, we found several significant differences in the gender comparisons, with females rating nearly forty percent of the importance items significantly higher ($p < 0.05$) than males. Items relating to Utility/Usefulness and Appearance of the prosthesis were more likely to receive significantly higher ratings from females. For example, in the Appearance category, the mean score for the appearance of the prosthesis was 91.9 for females, while the mean scores for males averaged 55.6 ($p < 0.000$). In the Utility category, females' mean score of importance for the energy required to use the prosthesis was 96.9 while males' mean scores averaged 86.5 ($p < 0.001$). Females also reported significantly higher scores for the importance of keeping the prosthesis from smelling badly (97.3 vs. 83.5, $p < 0.000$) and keeping the prosthesis from making noise (95.1 vs. 81.0, $p < 0.003$).

There were a few significant differences in the importance of characteristics found between age groups and between those with and without diabetes. Younger respondents (<65) rated "the ability to walk in close spaces" ($p<0.021$) and "the ability to walk on slippery surfaces" higher than those 65 or older ($p<0.031$). Persons with diabetes rated "the ability to walk up and down steep hills" significantly lower than those without diabetes ($p<0.009$). Females, diabetics, and those with transtibial amputations rated the durability of the prosthesis cover as more important than persons with a transfemoral amputation ($p<0.035$). There were no significant differences between any of the subgroups on the psychosocial scales.

Four Themes Identified in Open-ended Responses

Comments about the best and worst qualities of the prosthesis paralleled the responses to the questions about importance. Many respondents indicated there was nothing that they wanted to change about their prosthesis. Several wrote that they could not think of anything that would improve their activity except having their original limb back. Others reported having solved problems or still having problems to solve. In reviewing all of the comments, participants identified four general areas that were involved in the overall evaluation of one's prosthesis.

Theme One: The Fit of the Socket with the Residual Limb

Whether respondents were complimentary or critical, the topic most often mentioned was the fit of their residual limb with the socket. This matched the quantitative finding that the fit of the prosthesis was highly important to most respondents (**Table 2**). Persons with silicone suspension sleeves reported that this equipment improved the fit of their prosthesis. However, several respondents had difficulty adapting to a silicone sleeve. Sweating was commonly reported to affect the interface between the limb and the socket or suspension system. One person asked if a material could be designed to wick the sweat away from the residual limb. Several others would prefer not to be required to use creams or powders in order to don the prosthesis. Respondents who had experienced rashes, blisters, and ingrown hairs associated with wear, reported that this affected their ability to use the prosthesis and hoped for future improvement in this area. A common problem was the difficulty in maintaining socket fit due to a change in body weight or to temporary swelling of the residual limb. Women reported this problem occurred during their menstrual cycle. These respondents expressed a desire for a more forgiving socket that could accommodate small changes in residual limb size. Certain activities, such as getting in and out of a car or out of a chair, were cited as a threat to the integrity of the prosthesis suspension. Several subjects with transfemoral amputation identified problems with the valve that is commonly used to attach the limb. One person reported that the valve unlocks when he rides his motorcycle. Several respondents complained that the valve tore holes in their clothing.

Theme Two: The Mechanical Functions of the Prosthesis

Many observations were voiced about the moving parts of the prostheses. The respondents spoke of the structure, the construction, or just the "way it works." Persons with transfemoral amputations were particularly interested in knees that would lock and unlock reliably in more than one or two positions. They would like to be able to kneel, to stoop, or to be free moving (e. g., ride a bicycle). Several respondents suggested that ankle joints with adjustable alignment "from side to side and fore to aft" would be desirable. Many persons spoke fondly of the flexibility of their prosthetic foot, while others expressed a need for more or less flexibility.

Others mentioned that they valued the durability, ruggedness, or dependability of their current prosthesis. One man reported, "You wouldn't believe what I put this poor thing through." He added that his "weekends are spent on road- or mountain bikes, sailing or sky-diving." From several of the respondents' comments, it became apparent that any of the moving, and some of the non-moving, parts can create noises. These sounds were universally disliked, and the absence of noise was applauded. The size and adaptability of the prosthetic foot in relation to shoes and boots was mentioned. Often, the comment included a request for an adaptable foot that would allow him or her to wear shoes with different heel heights.

Theme Three: Other Qualities of the Prosthesis

For many respondents, the bulk of the limb made it difficult for them to wear certain clothing (e. g., to "get my jeans on"). A woman volunteered that the bulk "looks UGLY when I wear slacks." However, making the best of things, another woman reported, "I love that my foot has toes so I can polish the nails." The weight of the current prosthesis was discussed in terms of good and bad experiences. The common point being made was that getting the weight correct matters a lot. A quality that received wistful mention was the desire to be able to experience wet conditions safely. "If only the prosthesis could be made to withstand water...", wrote one person. Others expressed the desire to shower or swim with a prosthesis.

Theme Four: Adaptation with Support from Others

A final question that solicited general comments about life with a prosthesis was answered by over half of the respondents (54 percent). Having a good prosthetist was listed as an important part of having a good life. Several respondents mentioned working together with their prosthetist over years to solve problems as they arose. Others said in various ways that they greatly value having a way to get around other than in a wheelchair. One gentleman tersely wrote, "It is not like having the real thing, but it beats the alternative!" Another person volunteered, "I have been putting up with an ill fitting prosthesis for 11 years. I was able to obtain my present one due to the Washington State DSHS and to Medicare. If I had known how good the present prosthesis would be, I would have robbed a bank to get one. My last 11 years would have been drastically changed for the better."

General Comments from Respondents

General advice was offered for living with a prosthesis. For example, "I feel support groups are extremely important. Doctors and therapists are also important, but they cannot understand the frustrations an amputee goes through unless they are an amputee." Another such comment was, "A great deal of patience is required, and during the adjusting time encouragement is needed along with support from family members." "It is a great shock when one really comes to cope with losing a limb." Many other people described how helpful it was for them to have a positive attitude. "I like to be challenged and recovering mobility after the accident/loss was part of my desire to 'win.'" "Things just happen and you learn to live with them in the best way possible." One respondent summed up his recipe for a good life with a prosthesis: "Good prosthetist, good attitude, very active, and lots of practice."

For some respondents, other aspects of their health were more important than the amputation, such as other trauma received at the same time as the amputation or more recent disease processes. Several respondents commented that they have learned to live with pain and not pay

attention to it anymore. Others have developed problems that they attributed to having worn a prosthesis for years. One veteran reported, "[Over] fifty years of [wearing] a prosthesis I have messed up my back, hips, and legs. I have a very modern prosthesis now and the fit is real good, but I walk worse on it than I did on the wood ones. I walk worse because of what it has done to my body."

DISCUSSION

Each respondent in this project had lost some part of a lower limb and was living with a functional prosthesis. There are unique issues faced by this group of people. The most important function of the prosthesis was to enable walking and the most important characteristic of the prosthesis was the way it fit the residual limb. This was evident from both sources of data--the ratings of importance and the open-ended comments. While this is not surprising, many of the other comments were less obvious and may provide some insight into living with a prosthesis.

Since residual limb health affects the fit of the prosthesis, it was also a high priority for all respondents, as indicated by the importance assigned to avoiding blisters, sores, and rashes. Additional comments were made about the care of the residual limb in relation to using a prosthesis. Changes in body weight, the method of suspending the prosthesis, and controlling skin irritations, especially in warm weather, were mentioned.

While the subgroup numbers were small in some cases, we reviewed the comments to determine if some groups had different opinions about the importance of certain qualities of the prosthesis. Group size was a problem especially in reviewing gender differences. Findings were reported due to their marked differences. These findings should be replicated using a larger number of women, but they suggest there may be real differences in rating the importance of the appearance of the prosthesis by gender. A surgeon and study team member (DGS) reported having made a decision between a Syme's ankle level versus a transtibial amputation on a female patient based on the fact that the subsequent prosthesis is very bulky around the ankle and is not very satisfying cosmetically. The importance of having such a discussion with patients is supported by our data. Women as a group rated prosthetic balance, comfort while standing, the texture of the prosthesis against skin, and the required energy expenditure to ambulate as more important than did the men in the sample. The women in this sample were also more concerned with prosthetic odor than were the men.

Few significant differences were found in the opinions of older versus younger age groups or when we compared persons who had a recent versus a long-standing amputation. Persons with more recent amputation (less than 5 years) were significantly more likely to identify the importance of the texture of the prosthesis against their residual limb.

In an effort to be able to generalize to persons with functional lower limb prostheses, we recruited persons with unilateral amputation who were using their prosthesis at least five days a week. The vast majority of our respondents were male, which may be due to recruiting through a

veteran's hospital. However, we also sought persons through a regional trauma hospital and most of these persons were also male. Since the majority of war and trauma-related amputations occur among males in our society, our sample may reflect the gender distribution of amputations for these causes in our society. Persons having amputations due to disease progression probably would be more evenly apportioned by gender. The distribution of levels of amputations in our sample is consistent with most other studies; about 30 percent of our respondents had a transfemoral amputation. There are probably additional, unique conditions that exist for persons with Syme's, through-the-knee, or bilateral amputations (conditions for which we have little or no input), but for whom most of the issues in this paper would likely apply. Our sample was drawn from people living in the northwest section of the country. Regional differences may be present as far as access to competent prosthetic care; this study only represents our experience. However, the sample for this study is composed of a cross section of persons whose amputations have occurred over a wide time frame, at different ages, and for many different reasons.

As with all research, choices in design and execution have consequent strengths and weaknesses. The primary purpose of administering the original, field version of the PEQ was to gather enough information to shorten it for future research by choosing the better questions and forming scales (groups of questions) to address multiple life domains. This study required us to

- review extensive literature
- interview support groups for persons with amputation and their caregivers
- monitor on-line chat groups
- solicit information through open-ended questions.

This provided us with rich exploratory data about the concerns of our respondents. However, we were able to recruit only 92 individuals who met our broad criteria; and of these, only 13 were women. As a result, the gender findings should be viewed with caution until they have been tested in more females with amputation.

As clinicians, it can be puzzling to interpret and apply group means to a decision about an individual patient. Quality of life is a concept that is unique for each patient, and yet, the health status scores listed in this report describe an average score for a group or subgroups of patients. By also including comments from individuals, one can begin to understand the variation within a group. The persons living with a lower limb prosthesis scored significantly lower than average persons without an amputation on all scores but mental health. Yet, some of our respondents were extremely active and had high health status scores. The average of a group does not focus on the best and the worst experiences. In fact, the whole group contains some high scores, many in the mid-ranges, and fewest at the very low levels. The quotations have been included to provide a sense of the ranges of experience.

Four themes emerged that identify areas for attention in prosthetic care and future research: fit, mechanical function, non-mechanical function, and adaptation with support. From the information we gathered in this survey, we can conclude that many of the respondents are being well served by their prostheses. However, a small percentage of participants were living with prosthetic problems that could be resolved. Additional patient education and scheduled return visits to the prosthetist might alleviate some of these problems. Education about what can be expected would

help persons with amputations to feel it is acceptable to complain when something is wrong. For example, when a prosthesis is making noise, it usually indicates a mechanical problem that can be fixed; thus, it is not necessary to just "live with it."

The questions in the PEQ, when asked by a caregiver, could prove to be a springboard toward defining problems and improving the function of a prosthesis. These questions include the importance of various activities to the person and whether the prosthesis helps or hinders the wearer in the activity. A plan for continuity of a relationship with the prosthetist could identify changes in the mechanics or wear of the prosthesis that could affect other joints over time. These visits could also be used to rehearse and reinforce the performance of prescribed back exercises to maintain strength and mobility. Additional education about the management of the interface of the socket with the residual limb, including skin care and maintenance of a clean prosthesis, might reduce the presence of skin irritations. Among our respondents, some persons did not appear to understand the use of extra socks to adjust for mild weight changes. Rather than putting up with these problems, they could be brought to the attention of a caregiver; thus, signaling the need for a better fitting socket. Learning of a person's interest in performing new activities would warrant a description of the types of accommodations that can be made to use a prosthesis for this new activity. Because of the problems encountered with weight gain, it is particularly important to facilitate as much activity as possible.

As some of the respondents mentioned, potential costs can be a barrier to seeking care. It is incumbent upon a health care system to address this possibility and its impact on patient function and quality of life. Caregivers should be familiar with possible referral sources and should inform patients about them.

Future research should examine whether the problems expressed by our respondents can be ameliorated through ongoing education and by carefully attuned prosthetic care. Studies can be formulated to test the suggested differences within subgroups. It is with sincere interest in the well being of persons with lower limb amputation and with great respect for the wonder and complexity of the human body and spirit that we encourage continuing research to assist with adaptation to a lower limb amputation and prosthesis.

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