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### From satisfaction to expectation

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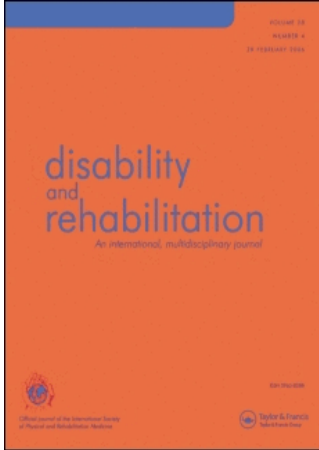
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### From satisfaction to expectation: The patient's perspective in lower limb prosthetic care

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RESEARCH PAPER

## From satisfaction to expectation: The patient's perspective in lower limb prosthetic care

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### Abstract

**Purpose.** To obtain information about the wishes and experiences of patients with a lower limb amputation with regard to prosthetic prescription and their exchange of information with the healthcare providers.

**Method.** Design: Cross-sectional questionnaire. Setting: Outpatient clinic of a Rehabilitation Centre. Study participants: A random sample of patients with a lower limb amputation ( $n = 81$ ). Main outcome measures: In analogy with the QUOTE questionnaire a focus group technique was used. Prosthetic users formulated 24 specific items, which were of importance according to them. The items were divided into 4 categories: (i) service demand, (ii) prosthetic prescription, (iii) information, (iv) insurance aspects. The questionnaire consisted of two sets (A and B) of 24 items rating importance of items and experience in everyday practice. To identify different dimensions within the 24 items, a factor analysis in SPSS was performed for lists A and B followed by a varimax rotation. Impact factors were calculated by multiplying the mean score of importance on an item with the percentage of patients that experienced this item as negative.

**Results.** A total of 113 questionnaires were sent by e-mail with a response of 73%. The outcomes of the questionnaires resulted in 2 sets of information: One concerning the importance of several items in the process of prosthetic prescription, the other the experience of the prosthetic user about those items. By multiplying the scores on importance by the percentage of negative experience per item (impact score) points of improvement for clinical practice were formulated.

**Conclusions.** A discrepancy between the needs of patients and what they experience in their contacts with clinical professionals as the most important dimension was noticed. A questionnaire with specific items for a homogeneous target group is a good method to formulate points of improvement for clinical practice in healthcare.

**Keywords:** *Healthcare services, patient satisfaction, patient experience, questionnaire, prosthetic prescription, lower limb amputation*

### Introduction

The role of the patient in the process of healthcare itself is of increasing importance [1–6]. In The Netherlands a law has been issued that states that participation of clients in an advisory board or otherwise is required in healthcare institutions [7,8]. According to this law, treatment plans have to take patients' wishes and expectations into account. This applies also in the provision of medical aids [9,10].

There are limitations to the use of traditional questionnaires in assessing patients' wishes and expectations [11]. High satisfaction scores and

no expression of wishes and expectations are obtained in traditional questionnaires due to a lack of specific questions regarding the nature and consequences of the disorder and the health care needed [7,12,13]. Therefore, these questionnaires cannot be used as an instrument for assessing the expectations and needs of the patients [13,14].

The role of the patient has changed into that of a consumer in the last decades and, especially in the field of prosthetics and orthotics (P&O), measurement of patient satisfaction alone has become of less interest [10]. Nowadays, patients are seen as experienced experts who know how to formulate

their wishes and demands regarding the processes and contents of healthcare services. Therefore, a questionnaire has to fulfil two important requirements [15]: (i) the subjects in the questionnaire have to correspond to the experiences of the patient category for which the instrument is intended; (ii) patients have to be involved in the development process of the instrument from the start.

To improve the quality of care for patients with a lower limb amputation in The Netherlands the development of a clinical guideline for prosthetic prescription was set up. This guideline development project was commissioned by the Dutch Health Care Insurance Board. Parts of this project are a systematic literature review and the systematic analysis of the clinical experts' opinions regarding prescription criteria and the intended use of a prosthesis [16,17]. In a study regarding prosthetic prescription and functioning with an upper limb prosthesis Postema et al. concluded that the wishes and opinions of the patients did not match the opinions held by the clinicians [18]. Hence, the goal of the present study is to obtain information about the wishes and experiences of patients with a lower limb amputation regarding prosthetic prescription and the exchange of information with the healthcare providers.

## Methods

For the assessment of patient's wishes and expectations we developed a questionnaire based on the QUOTE (QUALity Of care Through the patient's Eyes) instrument. QUOTE questionnaires were developed within a research project on quality of care from the patient's perspective in The Netherlands [13]. These questionnaires already existed for several categories of patient's with severe physical limitations [12]. Quality of care is defined as the degree to which perceived performances of health care services meet the needs of patients with respect to important aspects. In the development of the QUOTE questionnaires the patient has been given a central position. A QUOTE questionnaire contains three dimensions: (i) patient experience concerning healthcare aspects, (ii) importance of certain aspects according to patients, and (iii) an impact factor based on the multiplication of these two aspects. These judgements are expressed as quality improvement scores. In the development process of the QUOTE instrument, described in this paper, patients with a lower limb amputation were participating. The questionnaire reflected the multidimensionality of the care-giving process and included generic and category specific quality aspects [14,15].

Consistent with the preceding QUOTE instruments the focus group technique was used [13]. At first, four experienced prosthetic users were invited

to formulate the items which they thought to be of importance in both prosthetic prescription and the supply of a prosthesis. These four prosthetic users were selected based partly on their age ( $57 \pm 14.2$  years (mean  $\pm$  SD)) and partly on their experience with prosthetic care and patient's demands (being either representative of a prosthetic user's group or having an advisory function for a rehabilitation centre or the P&O facilities). An existing questionnaire for people with a physical handicap was used as a discussion format and probe [13,19].

This Dutch Quote instruments for disabled people contained 16 general importance and performance indicators [13]. Based on this questionnaire, category-specific items for lower limb amputees and prosthetic care were formulated by the focus group. These items were more precisely formulated and divided into categories by the researchers. Thereafter, the focus group verified these items and then a second group of amputees tested the aforementioned items with regard to their clarity and usefulness. The participants of this group ( $n = 16$ ) were randomly chosen from a group of prosthetic users who were visiting the outpatient rehabilitation unit in our rehabilitation centre at 2 successive prosthetic consultations. This group consisted of 9 males and 7 females with a mean age of  $58.9 \pm 21.2$  years (mean  $\pm$  SD). After this second focus group tested the items, some items were either deleted or more clarified, which resulted in a list of 24 items. These items were divided into 4 categories, which were all part of the prosthetic prescription process: (i) service demand, (ii) formulation of the prosthetic prescription, (iii) training, information and aftercare, (iv) claim and insurance aspects.

The questionnaire consisted of two parts. In part A the participants were asked to rate the importance of each item on a 4-point scale (1 = 'not important', 2 = 'fairly important', 3 = 'important', 4 = 'extremely important'). In part B the same 24 items were presented, but now with the question if the participants had positive or negative experiences with these items in daily practice. The latter was defined as the clinical practice in which the patient contacts the Medical Doctor in Physical and Rehabilitation Medicine (MD in P&RM), the Prosthetist (CP) and the Physical Therapist (PT). This 4-point scale ranged from no to yes (1 = 'no', 2 = 'not really', 3 = 'on the whole yes', 4 = 'yes'). Finally, the patients had to complete a small questionnaire with information regarding their age, the level of amputation, the reason for amputation and whether they were satisfied with the functioning and cosmetics of their prosthesis.

The questionnaire was sent to 113 experienced prosthetic users from the age of 18 onwards. The potential participants were randomly selected from a list of 300 amputees who visited our outpatient

department in the years 2001 and 2002 (Rehabilitation Centre St Maartenskliniek).

### Analysis

To identify different dimensions of healthcare in lower limb amputees, a factor analysis was performed for list A and B separately, followed by a varimax rotation. To determine the number of factors a screeplot was studied and the Kaiser rule (eigenvalue > 1) was applied. P-factor was defined as having at least 4 items that each loaded (> 0.40) on that factor. Each item was categorized in the factor on which it had the highest (absolute) loading. To calculate the impact factors the following formula was used: impact factor = (mean score of importance on an item) × (percentage of patients that experienced this item as negative). For the latter score the four response categories were dichotomized into percentages 'yes' and 'no'.

### Results

A total of 113 questionnaires were sent by mail, 82 of which were filled in, a response of 73%. From the non-respondents, five patients had died, two were not able to fill in the questionnaire, one person had moved and six patients were not satisfied with the prosthesis or the service of the care providers and were therefore not interested in filling in the questionnaire. Seventeen patients failed to respond at all. This implied a net response of 82%. The demographics of the respondents and non-respondents are given in Table I. There was no statistical difference between the groups regarding age, gender, level of amputation and reason for amputation.

Relevant outcomes are given in Tables II and III. The principle component analysis of the 24 items of part A shows that 6 factors accounted for 64% of the total variance (see Table II). In practice the items loaded slightly differently on factors than originally thought. Seven items were added to the first factor (information), four items to the fourth (insurance), two items to the fifth factor (prosthetic prescription) and one item to the sixth factor (care providers). One of the criteria constituting a factor was that a factor had to have at least four items. Hence, the last two factors were excluded (see end of Table II).

The principle component analysis of part B (experience) showed that six factors accounted for 72% of the total variance (see Table III). These items were also ranged differently from the original questionnaire. Seven items were added to the first presupposed factor (service demand), five items to the second factor (prosthetic prescription), four items to the third factor (living with a prosthesis), four items were added to the fourth factor

Table I. Patient demographics.

	Respondents (n = 82)	Respondents + Non respondents (n = 113)
Age		
Mean ± SD	55.8 ± 15.9	58 ± 15.2
Gender		
Male	51	69
Female	31	44
Level of amputation		
Transtibial	35	55
Knee-disarticulation	13	16
Transfemoral	34	42
Reason for amputation		
Diabetes mellitus	10	11
Vascular disease	19	31
Trauma/tumour	42	50
Infection/other	11	21
Satisfied with the cosmetics of the prosthesis*		
Yes	70	–
No	11	–
Satisfied with functioning with the prosthesis*		
Yes	56	–
No	25	–

\*One respondent gave no satisfaction rating because he had his prosthesis for just 1 day.

(prosthesis after care), three to factor 5 (insurance) and one item to factor six (training). The last two factors were excluded because they had less than four items (see end of Table III).

When comparing Tables II and III one can notice a difference between part A (importance) and B (experience) of the questionnaire. There was also a difference in the way of ranging the items over the various factors in both parts. Therefore, the outcome of the questionnaire resulted in two sets of information, one concerning the importance patients attributed to the items in the process of prosthetic prescription, the other concerning the experience in daily practice with the items of importance for the prosthetic user.

### Discussion

In our view the questionnaire developed with the help of a prosthetic-user focus group is a list, both concise and precise with relevant items for patients who are potential users of a lower limb prosthesis. However, the classification of the items under the several factors was different from what was originally hypothesized (see method section). For both part A and part B the factor analysis showed a slightly different classification of items (see Tables II and III).

From other studies it is known that over 80% of the problems concerning the quality of healthcare are due to shortcomings in the system, processes,

Table II. Factor analysis questionnaire part A rating 'importance'.

Item	% missing	Mean	SD	Factor
<b>Factor 1 Information</b> , eigenvalue = 7.7				
12 The PC give me information about what to do in case of prosthetic problems; for instance who to call in case something does not work	0	3.23	0.81	0.79
13 The PC inform me about the existence of patient associations	0	2.16	0.94	0.53
15 The PC inform me if I can return to my former job	6	2.45	1.11	0.43
16 The PC explain to me what kind of shoes I can wear with my prosthesis; they explain to me which combinations of shoes and prosthesis are possible	0	2.90	1.03	0.64
17 The PC explain to me how to use the prosthesis; they inform me about the functional possibilities with my prosthesis	0	3.26	0.81	0.78
18 The PC inform me about the maintenance of the prosthesis	0	3.11	0.77	0.70
20 The PC inform me about the frequency and duration of visits to the clinic when getting a new prosthesis	0	3.07	0.78	0.72
<b>Factor 2 Prosthetic prescription</b> , eigenvalue = 2.1				
5 In the prescription process my opinion is decisive	1	2.93	0.79	0.79
8 In the prescription process my level of activity is of great importance	0	3.35	0.69	0.56
14 The PC inform me about the costs of the prosthesis and relating aspects	0	2.35	0.91	0.73
22 The PC let me decide how to spend my healthcare budget	9	2.61	1.00	0.70
<b>Factor 3 Service demand</b> , eigenvalue = 1.5				
1 The PC communicate well with me	0	3.27	0.61	0.74
2 The PC have sufficient knowledge of amputation aspects and prosthetics	0	3.51	0.59	0.71
3 The PC inform me in an understandable language	0	3.43	0.63	0.58
11 The physical therapist offers sports and dance activities besides a prosthetic training when I ask for this	0	2.54	0.91	0.43
19 The PC give me time to get used to a new prosthesis or changes to the old one and inform me about what changes have to be made in future	0	3.54	0.69	0.60
<b>Factor 4 Insurance</b> , eigenvalue = 1.4				
9 A new prescription (changes in the prescription) is given by an MD in P&RM and a CP and in consultation with me	1	3.47	0.59	0.50
10 A repeat prescription (no changes in the prescription) is performed by an MD in P&RM and a CP and in consultation with me	1	3.00	0.77	0.72
21 The costs of care regarding the use of a prosthetic limb will be covered by the insurance	0	3.40	0.77	0.54
23 The PC will prescribe a new prosthesis whenever necessary instead of waiting for the 3 year period laid down by the insurance company	0	3.49	0.74	0.73
24 It is the MD in P&RM and/or the CP who communicate with the healthcare insurer about a new prosthesis primarily	1	3.30	0.75	0.60
<b>Prosthetic prescription</b> , eigenvalue = 1.3				
6 In the prescription process the PC consider my needs in daily life (employment, hobby, sports)	0	3.38	0.62	0.52
7 The CP is informed about the latest developments on prosthetics	0	3.57	0.61	0.66
<b>Multidisciplinary team</b> , eigenvalue = 1.3				
4 The PC collaborate in a multidisciplinary team (MD in P&RM, CP, PT)	1	3.38	0.68	0.69

% missing, percentage missing values with 82 participants; Mean, mean score on this item, minimum score is 0, maximum score is 4; SD, standard deviation of the mean score; Factor, value after factor analysis; PC, Providers of Care; MD P&RM, Medical Doctor in Physical Medicine and Rehabilitation; PT, Physical Therapist; CP, Certified Prosthetist.

structure and practices of organizations [10,20–22]. Only a minority of the problems were traceable to a person who was not conscientious enough [10,20–22]. It is also known that patients are satisfied very easily with the healthcare items. Some 85% of patients are supposed to be satisfied with the care provided [10,21–23]. In our study high mean values were observed in both item sets. These mean values are directly comparable to each other and are an indicator of the importance of the item or the experience with it in everyday practice. For example,

item 11 (sports and dance combined with prosthetic training), item 13 (knowledge about patient associations) and item 14 (information about the costs of a prosthesis) have a relatively low mean score and are therefore judged as less important. The experience of patients with the care offered shows that there is also a low scoring on these items. Therefore, it seems that they get less attention from the care providers in relation to other aspects of care.

The standard deviation gives information on how unanimous the participants were in their judgement.

Table III. Factor analysis questionnaire part B rating 'experience'.

Item	% missing	impact score	Mean	SD	Factor
<b>Factor 1 Service demand</b> , eigenvalue = 8.9					
1 The PC communicate well with me	0	0.319	3.52	0.80	0.62
2 The PC have sufficient knowledge of amputation aspects and prosthetics	5	0.171	3.63	0.63	0.90
3 The PC inform me in an understandable language	1	0.167	3.68	0.65	0.88
4 The PC collaborate in a multidisciplinary team (MD in P&RM, CP, PT)	5	0.545	3.37	0.88	0.72
6 In the prescription process the PC consider my needs in daily life (employment, hobby, sports)	2	0.906	3.11	1.03	0.53
7 The CP is informed about the latest developments on prosthetics	12	0.711	3.6	0.62	0.83
19 The PC give me time to get used to a new prosthesis or changes to the old one and inform me about what changes have to be made in future	2	0.216	3.66	0.64	0.75
<b>Factor 2 Prosthetic prescription</b> , eigenvalue = 2.8					
5 In the prescription process my opinion is decisive	5	0.928	2.9	1.11	0.77
8 In the prescription process my level of activity is of great importance	4	0.131	3.28	0.99	0.77
9 A new prescription (changes in the prescription) is performed by an MD in P&RM and a CP and in consultation with me	7	0.736	3.36	0.95	0.69
10 A repeat prescription (no changes in the prescription) is performed by an MD in P&RM and a CP and in consultation with me	6	0.550	3.38	0.92	0.74
22 The PC let me decide how to spend my health care budget	22	1.052	2.42	1.31	0.66
<b>Factor 3 Living with a prosthesis</b> , eigenvalue = 1.8					
13 The PC inform me about the existence of patient associations	4	1.632	1.81	1.08	0.73
14 The PC inform me about the costs of the prosthesis and relating aspects	1	1.780	1.9	1.08	0.76
15 The PC inform me if I can return to my former job	18	1.257	2.24	1.22	0.82
18 The PC inform me about the maintenance of the prosthesis	1	1.138	2.95	1.07	0.50
<b>Factor 4 Prosthetic after care</b> , eigenvalue = 1.5					
12 The PC give me information about what to do in case of prosthetic problems; for instance who to call in case something does not work	0	0.512	3.48	0.98	0.74
16 The PC explain to me what kind of shoes I can wear with my prosthesis; they explain to me which combinations of shoes and prosthesis are possible	2	1.310	2.78	1.27	0.50
17 The PC explain to me how to use the prosthesis; they inform me about the functional possibilities with my prosthesis	1	0.754	3.23	1.00	0.46
20 The PC inform me about the frequency and duration of visits to the clinic when getting a new prosthesis	1	0.937	3.09	1.10	0.57
<b>Insurance</b> , eigenvalue = 1.2					
21 The costs of care regarding the use of a prosthetic limb will be covered by the insurance	2	0.913	3.20	1.22	0.71
23 The PC will prescribe a new prosthesis whenever necessary instead of waiting for the 3-year period laid down by the insurance company	12	0.936	2.96	1.24	0.51
24 It is the MD in P&RM and/or the CP who communicate with the healthcare insurer about a new prosthesis primarily	4	0.121	3.77	0.60	0.80
<b>Training</b> , eigenvalue = 1.1					
11 The PT offers sports and dance activities beside a prosthetic training when I ask for this	22	0.476	2.84	1.17	0.72

% missing, percentage missing values with 82 participants; Mean, mean score on this item, minimum score is 0 (bad experience), maximum score is 4 (good experience); SD, standard deviation of the mean score; Factor, value after factor analysis; PC, Providers of Care; MD P&RM, Medical Doctor in Physical Medicine and Rehabilitation; PT, Physical Therapist; CP, Certified Prosthetist.

In the item list where experience is rated (Table III) there is a great number of missing values on some items (for example item 15 concerning the employment situation). Probably this is due to the mean age of the study population with 75% older than 65 years and their matching experiences. Therefore, certain items could be of less importance for some participants. The knowledge of the care providers about aspects of prosthetic prescription (item 2), prescription of a new prosthesis on time (item 23) and the knowledge of the CP about the latest developments

on prosthetics (item 7) are judged as very important items.

In general, 4 large factors can be distinguished in the item set 'importance' as well as in the item set 'experience'. They both have the same headings in Tables II and III; however, they contain slightly different items. In the list 'importance' we can distinguish the dimensions information, prosthetic prescription, service demand and insurance. In the list 'experience' the same dimensions, however, come up in a different order, i.e., service demand,

prosthetic prescription, information and insurance. From the results of this questionnaire it can be derived that the respondents experience the care providers as highly qualified. Based on the high mean scores we can state that the care providers are seen as professionals who communicate in understandable language with the patient (item 30), who take the time needed by a patient as a guiding principle (item 19) and protect them from unnecessary communication with the healthcare insurance companies (item 24).

In general, impact scores can serve as a guiding instrument for improvements in the provision of care on service demands. From the impact scores used in this study a top-5 list of specific points was made. These items had to be improved in our own clinical practice. The care providers should give more information or attention to the patients about:

1. The existence of patient associations (item 13),
2. The aspects concerning costs of the prosthesis (item 14),
3. Cosmetic aspects of the prosthesis, especially shoes (item 16),
4. The possibility to return to their old job (item 15),
5. The maintenance of the prosthesis (item 18).

The results of this study, as far as it concerns measuring items regarding the role, attitude and professional knowledge of clinicians, cannot straightforwardly be generalized to other healthcare situations. This emphasizes the importance of the impact factor as a local instrument for improvement. There is a clear relationship between the height of the mean score on an item, the standard deviation of the values and the height of the impact score. On the one hand, this inspires confidence in the method of measuring these scores and its use as an indicator for improvement. On the other hand, if the mean score gets higher and the standard deviation smaller, the impact score becomes lower.

The importance of patient involvement in the prosthetic prescription process is underlined by the study of Postema et al. [18]. This study showed that the involvement of the patient was proportionate to the compliance of patients with regard to the use of an upper limb prosthesis. There was no clear agreement between the wishes and opinions of patients and the ideas of professionals about the compilation of prosthetic components and their functioning with the prosthesis. Therefore patients did not use their prosthesis or there was disappointment for patients and professionals.

There were some limitations to this study. The patients responding to the questionnaire were primarily older patients (mean age 56 years) with specific demands about care provision regarding

their prosthesis and other aspects. For the younger population of prosthetic users, wishes and expectations could be different. Therefore, the conclusions of this study cannot be extrapolated to the whole population of prosthetic users. Furthermore we selected only four experienced prosthetic users for the focus group to formulate the items for the questionnaire. A larger group could have stirred up more discussion on the items resulting in a slightly different set of items. However, the members of the focus group were experienced users of prosthetic and rehabilitation care and were also familiar with the demands of other prosthetic users because some participants of the focus group were members of the amputee association.

The following step in our research will be a nationwide study based on this questionnaire. It will be interesting to know whether a larger group of prosthetic users will rate the same items as important and if there are differences in 'importance' factors and experiences with clinical practice in different parts of The Netherlands. In future research the differences between subgroups regarding age and gender and satisfaction about the prosthetic are also of interest.

## Conclusion

We noticed a discrepancy between the expectations of patients and their experience in the contact with clinical professionals as most important dimension. The results of this questionnaire are useful in the process of guideline development for prosthetic prescription. A questionnaire with specific items for a homogeneous target group seemed to be a good method to formulate points of improvement for daily practice in healthcare.

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