Areas of Concern, Quality of Life and Life Satisfaction in Patients with Peripheral Vascular Disease

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Objectives: to explore the ways in which peripheral vascular disease subjectively affect patients and to relate these findings to validated measurements of quality of life (QOL) and life satisfaction.

Design: a cross-sectional study.

Subjects: eighty patients, with carotid artery stenosis (CAS), abdominal aortic aneurysm (AAA), intermittent claudication (IC) or critical limb ischaemia (CLI).

Methods: semi-structured interviews were used to explore the effect of the disease on the patients life situation. QOL was assessed by SF-36 and life satisfaction by LiSat-11.

Results: the SF36, LiSat-11 and our interview revealed two principal patterns: one for patients with CAS and AAA, and one for patients with IC and CLI. The interview revealed important areas affecting the vascular patient. Some of these areas: higher intellectual function, concern, sexual function, family concern and factors related to the operated areas were not covered by either the SF36 or the LiSat-11.

Conclusions: for a full understanding of how peripheral vascular disease affects the individual, disease specific questions need to be added to generic QOL instruments and measurements of life satisfaction.

Key Words: Quality of life; Life satisfaction; Peripheral vascular disease; Carotid artery stenosis; Aortic aneurysm abdominal; Intermittent claudication; Lower limb ischaemia.

Introduction

Vascular surgeons have traditionally focused on outcomes such as mortality, morbidity and graft patency. During the last decade, however, there have been an increasing number of studies investigating quality of life (QOL) in patients with carotid artery stenosis (CAS)1-5, abdominal aortic aneurysm (AAA),6-11 intermittent claudication (IC) and critical limb ischaemia (CLI).12-20 Owing to the current lack of a single quality of life scale for peripheral vascular disease a generic tool must be adopted.21,22 Some of the best known generic instruments have been validated in patients with IC and CLI.22-26 Each of these generic questionnaires has strengths and weaknesses.21,22,25,26

In this study, patients with CAS, AAA, IC and CLI were interviewed to find out what concerned them most about their disease and to what extent their QOL and life satisfaction were impaired. These answers were related to the results of the Short Form (SF)-3627-30 life satisfaction (LiSat)-11 instruments.41

Patients and Methods

The SF-36 contains 36 questions covering eight health domains: physical functioning, role limitations due to physical problems (extent to which physical health interferes with daily activities such as work, housework or school) bodily pain, general health perceptions (rating of personal health) vitality (energy level and fatigue), social functioning, role limitations due to emotional problems and mental health (general mood or affect including anxiety, depression and psychological well-being). An additional item, addressing health change over time, was recorded but not scored. For each dimension, question scores are coded, summarised and transformed into a scale from 0 (worst possible quality of life) to 100 (best possible quality of life). We used the Swedish version of the SF-36 which is validated in a Swedish population.31

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LiSat-11 is a self-administered checklist intend to characterise global life satisfaction (one item) and ten pertinent life domains. For each item the subject states her/his level of satisfaction along a 6-graded scale ranging from very dissatisfied (1) through dissatisfied (2), rather dissatisfied (3), rather satisfied (4), satisfied (5), to very satisfied (6). This check-list has been validated in a random sample in Sweden of 1475 men and 1335 women aged 18–74 years. The scale has been shown to be test-retest reliable.45 In different clinical investigations,43,44 good responsiveness of pertinent items have been demonstrated. It has been translated (forward/backward) and culturally adapted to 16 different languages. It has recently been shown that the 6-graded scale can validly be dichotomised into satisfied (grades 5–6) and not satisfied (grades 1–4).45 Factor analysis has shown that whether the full 1–6 graded scale or dichotomy 1–4 vs 5–6 is used, the 10 domains form a four factor construct: closeness (satisfaction with sexual life, partner relationship, family life), health (satisfaction with ability to manage simple self-care activities of daily living such as dressing, hygiene, simple transfers), somatic and psychological health, leisure (satisfaction with leisure, contacts with friends and acquaintances), providing (satisfaction with vocational/occupational situation and economy).45 Within these factors high degrees of internal consistency have been found. The recommendation is to use LiSat item-by-item. In the present study an age matched control group (n = 277, aged 65–74 years) was drawn from the total national sample for comparison.41

In a semi-structured interview the patients were also asked eight semi-structured questions with open answering alternatives (Table 1). These questions were designed after discussion with a clinical epidemiologist, a vascular surgeon, a nurse with knowledge of quality of life research and a life-satisfaction researcher who also is a psychotherapist. In addition the patients were asked about comorbidity and their social situation. The interviews took place in a quiet consulting room (all groups) or in the subjects’ home (some of the CAS- and AAA patients). The use of a tape recorder was piloted in the first interviews, but this was found to inhibit the patient. Instead, the interviewer took detailed notes of statements of the patient’s concerns using the patient’s own wording. The interviewer read the interview notes several times and classified statements into main categories, which were jointly discussed and revised in the research team until we found eight areas of concern which was repeatedly mentioned among the study participants.

The target was to include 20 patients (operated and not operated) in each of the sub-groups of peripheral vascular disease: CAS, AAA, IC and CLI. Recommended reporting standards in patients with lower extremity ischaemia32 defined the IC and CLI groups. We identified consecutive patients from the appointment schedule at the surgical outpatient clinic or (the CAS- and AAA-groups) through the hospital’s database. The interviewer (AH) phoned the patients one to seven days before their visit to the clinic and informed them about the study. Each patient was asked if she/he was willing to participate. All patients consented to participation. The interviewer is an experienced clinician but was not involved in the individual patient’s care. Some pertinent characteristics for each subgroup are shown in Table 2. Two patients were excluded because of dementia and two because of concurrent related diseases.

The ethics committee at Uppsala University approved the study. Statistical comparison between patient groups and an age matched population in Sweden were made using t-test for SF-3631 and Chi-squared test for LiSat-11.41 Since we found two patterns in the two questionnaires and our semi structured interview, one for patients with CAS and AAA and one for patients with IC and CLI, we dealt with these groups pairwise (CAS + AAA and IC + CLI) together in the statistical analysis. Statistical significance was defined as p < 0.05.

Results

There were no missing responses to the SF36 and 2.5% missing responses in the LiSat-11. The average time

Table 1. Semi-structured questions. Disease was defined as peripheral vascular disease.

<table>
<thead>
<tr>
<th>Question</th>
<th>Context</th>
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<tbody>
<tr>
<td>(1) What would you like to be able to do today that you can’t do due to your disease? Is your wish realistic?</td>
<td></td>
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<tr>
<td>(2) What have you denied yourself due to your disease?</td>
<td></td>
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<tr>
<td>(3) In what way do you think your relatives have been influenced by your disease? Who are your relatives?</td>
<td></td>
</tr>
<tr>
<td>(4) Has the pain, the scar, the wound, the amputation etc influenced you?</td>
<td></td>
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<tr>
<td>(5) Have you suffered from any social problems or problems such as anxiety?</td>
<td></td>
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<tr>
<td>(6) What factors do you think mostly influence the quality of life of other patients having the same disease?</td>
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<tr>
<td>(7) Many patients in your situation have sexual problems, is this something that concerns you?</td>
<td></td>
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<tr>
<td>(8) Do you feel anxiety about or confidence in the future?</td>
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for the interview was 16 min (range 5–30), for answering the SF36 14 (range 8–30) min, and for answering the LiSat-11 5 (range 1–8) min. Following a categorisation of the statements the following important areas were defined (all the limitations and disturbances mentioned below were considered associated to peripheral vascular disease):

**Physical functioning**
These patients are concerned about not being able to do what they want to do. They miss the ability to walk properly and take part in activities such as dancing, hunting or gardening. They are profoundly limited due to physical impairment and a typical statement is “My greatest wish is to be able to walk in the forest”. These patients often report a feeling of isolation.

**Social functioning**
These patients are concerned about limited relations with friends and family due to physical and psychological impairment. A typical statement is “I’m not able to take a walk with my neighbour, and I really miss that contact”. These patients also have a feeling of isolation.

**Sexual functioning**
These patients are concerned about a disturbance in their sexuality due to physical or psychological impairment. A typical statement is “Since the operation I am not able to get erection”.

**Anxiety/concern**
These patients are concerned about their disease, potential future complications and whether or not they have a concomitant disease. A typical statement is “I’m afraid of losing my leg” or “I’m afraid of having a stroke and then becoming paralysed and dependent on care”. This concern sometimes leads to a physical disability due to concern about disease related complications and a typical statement in this group is “I wish to be able to chop wood but I don’t dare because of the risk of rupturing my aorta”.

**Intellectual capacity**
These patients feel that they have some kind of regression of higher intellectual capacity, e.g. “I have difficulties taking part in advanced discussions”.

**Family concern**
These patients express concern that their family worries about them and are afraid of becoming a burden. A typical statement is “My wife and my son are afraid and concerned about a future amputation”.

**Pain**
These patients suffer from and are concerned about pain. Pain may also have a negative effect on their sleep. A typical statement is “If I could only get relief from the pain I would be happy again”.

**Factors related to surgery**
These patients are concerned about the appearance of the scar, numbness, hernia and a feeling of mutilation if amputated. One statement was “I feel disfigured”.

We studied the occurrence of these eight concerns in the four patient groups. The non-operated CAS patient is mostly influenced in areas of anxiety/concern, family concern and intellectual capacity and the operated CAS patient in the area of anxiety/concern. Regarding the open questions, 1 and 6 (Table 1), the area of anxiety/concern is most important in the CAS patient.

The non-operated AAA patient is mostly influenced in areas of anxiety/concern, family concern and the operated AAA patient in areas of sexual functioning and anxiety/concern. Regarding the open questions, the area of anxiety/concern is most important in the AAA patient.

The non-operated IC patient is mostly influenced in areas of physical functioning and social functioning and the operated IC patient in areas of physical functioning, social functioning, sexual functioning, anxiety/concern and family concern. Regarding the open questions, the areas of physical functioning and social functioning are most important in the IC patient.

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**Table 2. Patient characteristics and planned or already performed treatment.**

<table>
<thead>
<tr>
<th></th>
<th>Median age (years)</th>
<th>Age range (years)</th>
<th>Male/female</th>
<th>Conservative management or follow-up</th>
<th>Planned op or angio, PTA</th>
<th>Operated or PTA elective/acute</th>
<th>Not operable</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAS</td>
<td>20</td>
<td>71</td>
<td>56–81</td>
<td>12/8</td>
<td>0</td>
<td>8</td>
<td>11/0</td>
</tr>
<tr>
<td>AAA</td>
<td>20</td>
<td>71</td>
<td>59–82</td>
<td>18/2</td>
<td>7</td>
<td>3</td>
<td>4/6</td>
</tr>
<tr>
<td>IC</td>
<td>20</td>
<td>67</td>
<td>20–82</td>
<td>10/11</td>
<td>7</td>
<td>3</td>
<td>10/0</td>
</tr>
<tr>
<td>CLI</td>
<td>20</td>
<td>73</td>
<td>54–88</td>
<td>7/13</td>
<td>3</td>
<td>7</td>
<td>11/0</td>
</tr>
</tbody>
</table>

PTA = percutaneous transluminal angioplasty.
The non-operated CLI patient is mostly influenced in areas of physical functioning and social functioning, anxiety/concern, family concern and pain and the operated CLI patient in areas of physical functioning, social functioning and family concern. Regarding the open questions, the areas of physical functioning and social functioning are most important in the IC patient.

The results from the interview are displayed graphically in Figs 1–4. The graphs reveal two main patterns, one for patients with CAS and AAA, and one for those with IC and CLI. When measuring health related quality of life with SF36 (Fig. 5), patients with CAS and AAA once again show a similar pattern and achieved the quality of life of the healthy population except in the domains of bodily pain and emotional role where the examined group had better quality of life values. As in the interview, patients with IC and CLI also have a common pattern. IC and CLI patients have a statistically significant deterioration in physical functioning, physical role, bodily pain, general health and social functioning compared to a healthy population. The same overall pattern with different profiles for CAS-AAA and IC-CLI patients respectively was seen in the LiSat-11 assessment (Fig. 6). Both groups show a statistically significant deterioration compared to a healthy population in satisfaction with life as a whole, sexual life and physical health. The CAS-AAA group had a worse vocational situation and the IC-CLI group less good leisure satisfaction and partner relationship than the healthy population.

Discussion

We explored the ways in which patients with four different manifestations of peripheral vascular disease are affected by their condition from their own subjective perspectives. The SF36, the LiSat-11 and our semi-structured interview together formed two main patterns: one for patients with CAS and AAA, and one for patients with IC and CLI. This has not been shown within one and the same study before. These patterns were formed in spite of the fact that the clinical stages differed from patient to patient within the groups. The findings indicate that while patients with CAS and AAA are concerned about a serious disease they have no or mild symptoms, but patients with IC and CLI are both concerned and truly physically impaired by their disease. The interview also revealed some areas of concern to the vascular patient not covered by the SF36 and at the same time gave some substance to the different domains in that instrument.

In our semi-structured interview question number 1, 2, 3, 6 and 8 were open and the others more direct. In the semi-structured interview one of the eight questions (no. 6) explicitly asked the patient about his/her opinion about areas of concern in regard
Fig. 2. The eight important areas extracted from the interview and how the patient with abdominal aortic aneurysm, both operated and non-operated, are affected by the disease in that specific area. The figures represent the percentage of patients not describing any disturbance in that certain area. The bigger area the better the quality of life.

Fig. 3. The eight important areas extracted from the interview and how the patient with intermittent claudication, both operated and non-operated, are affected by the disease in that specific area. The figures represent the percentage of patients not describing any disturbance in that certain area. The bigger area the better the quality of life.
Fig. 5. Variation in SF36 quality of life domains in patients with carotid artery stenosis (CAS), abdominal aortic aneurysm (AAA), intermittent claudication (IC) and critical limb ischaemia (CLI) compared to an age matched population norm. The bigger area the better the quality of life. The CAS-AAA group had significantly higher scores than a normal population in bodily pain and role emotional dimensions. The IC-CLI group deteriorated significantly compared to a normal population in the dimensions of physical functioning, role limitations due to physical problems, bodily pain, general health perceptions and social functioning.

Fig. 4. The eight important areas extracted from the interview and how the patient with critical limb ischaemia, both operated and non-operated, are affected by the disease in that specific area. The figures represent the percentage of patients not describing any disturbance in that certain area. The bigger area the better the quality of life.
to life quality and the actual disease. Furthermore, the semi-structured design made it possible for the patients to express their experiences in regard to the different areas. Thus, we judged that there was little risk of false promotion of any domain. Topics related to the content of questions 4, 5 and 7 may have received selectively more attention but they do not dominate the results.

Among the patients with CAS we noted concern about disturbance in higher intellectual functioning in the patients who had not yet undergone operation. Studies, using neuropsychological tests, have suggested a deteriorated intellectual capacity before CEA with an improvement after surgery, but the findings have been questioned. In the study by Sirkka et al., 17% of the patients mentioned fear of developing paralysis or stroke. The SF36 does not survey higher intellectual capacity and has no question regarding concern about the disease and future complications.

Both the operated and the non-operated AAA patients were limited in heavier physical exercise due to concern about complications. Among the surveillance group, 40% were worried about the disease and future complications while none of the operated patients expressed this concern. Previous studies have shown decreased preoperative quality of life levels but found no difference in quality of life after surgery for elective or ruptured AAA compared to matched population based samples.

Forty per cent of all of the operated patients reported decreased sexual ability after surgery. Studies on sexual dysfunction after grafting for AAA are scarce. Lee et al. found in a questionnaire that 67 of 68 men reported erectile dysfunction after surgery. About 35–40% of the patients operated on for elective and ruptured AAA complain of decreased potency. The SF36 has been validated in AAA patients but does not explore the area of sexual dysfunction. The CAS-AAA group deteriorated significantly compared to a nationally representative population in the sexual life domain measured by LiSat-11. The CAS-AAA group showed no difference from a normal population in health related quality of life measured by SF36 in all domains except bodily pain and emotional role where the group exceeded normal values. Again, the fact that this group of patients has a serious but often asymptomatic disease might explain the high quality of life figures through a psychological reorientation of life goals.

Fig. 6. Variation in LiSat-11 life satisfaction domains in patients with carotid artery stenosis (CAS), abdominal aortic aneurysm (AAA), intermittent claudication (IC) and critical limb ischaemia (CLI) compared to an age matched population norm. The figures represents the percentage of patients satisfied with life (scalegrades 5-6) within that certain domain. The bigger area the better life satisfaction. The CAS-AAA group deteriorated significantly from population norm in dimensions of life as a whole, vocational situation, sexual life and somatic health. The IC-CLI group deteriorated significantly in the dimensions of life as a whole, economy, leisure, sexual life, personal ADL, partner relationship and somatic health.
We found that more than 90% of the patients with IC and CLI were concerned about their physical limitations and the negative effect of this on their social life. The patients with CLI also suffered from and were distressed by pain. This is in line with other reports and patients with limb threatening ischaemia report a health status comparable to that of patients seriously ill with cancer. Physical functioning, role functioning, bodily pain and general health perception are similar or worse than in patients with congestive heart failure or recent myocardial infarction. In the present study, the patients with IC showed a similar pattern to the patients with CLI. When using the SF36, the IC-CLI group showed deterioration in physical function, role function, bodily pain, general health and social function, and when using the LiSat-11 patients with IC-CLI showed diminished satisfaction with life as a whole, economy, leisure situation, sexual life, personal ADL, partner-relationship and somatic health.

Some issues seem to concern all four groups similarly. Approximately 30% of the patients worried that their families were concerned about their health status. Twenty per cent of the operated patients complained about complications in the operated area or reported a feeling of mutilation. The patients with CLI also suffered from these areas or reported a feeling of mutilation.

Health related quality of life should be distinguished from overall quality of life since the latter may encompass not only health related factors but also many non-medical aspects, such as employment and family relationship. If this distinction is neglected, the impact of health related factors may be overestimated and the effect of non-medical phenomena undervalued. In our study we found that domains in the SF36 and the LiSat-11, that may be thought of as measuring the same aspects of quality of life, correlated poorly. This finding could perhaps be expected but is nevertheless important. One major difference between the questionnaires is that the SF36 measures what the patient is capable of and the LiSat-11 measures the patient’s level of goal achievement. Measuring an aspiration-achievement gap might be just as, or more important than studying what the patient actually is capable of. This gap is obvious for instance in the domain of physical functioning in patients with IC and CLI in our study.

Our proposal, when measuring quality of life in patients with peripheral vascular disease, is to use one of the generic questionnaires, the SF36, and add one questionnaire measuring non-health related quality of life, i.e. the LiSat-11. To complete the portfolio we also suggest condition specific questions as described below, questions that could also be useful when used by nurses or physicians in their daily contacts with vascular patients:

**CAS**

Questions about higher intellectual functions. Questions regarding concern about the disease and future complications.

**AAA**

Questions about sexual ability. Questions regarding concern about the disease and future complications.

**All groups**

Questions regarding what the patient would like to be able to do, something they can not do today due to their disease. Questions about the family concern about the patient. Questions about the operated area or the amputated limb.

**Acknowledgements**

Financial support for this study was received from Swedish Medical Research Council, Dalarnas forskningråd and the Olaisson trust. The authors thank Marianne Omne-Pontén for helping us designing the semi-structured questions and Charles Taft for helping us with questions concerning SF36.

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Eur J Vasc Endovasc Surg Vol 24, September 2002
Quality of Life and Life Satisfaction in Vascular Disease


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Accepted 12 March 2002