Domains that Determine Quality of Life in Vascular Amputees

Bjoern D. Suckow,[1] Philip P. Goodney,[2] Brian W. Nolan,[2] Ravi K. Veeraswamy,[3] Patricia Gallagher,[4] Jack L. Cronenwett,[2] and Larry W. Kraiss,[1] Salt Lake City, Utah; Hanover, New Hampshire; Atlanta, Georgia; and Boston, Massachusetts

Background: Although patients with critical limb ischemia (CLI) commonly undergo major limb amputation, the quality of life (QOL) of this group remains poorly described. Therefore, we sought to describe which domains vascular amputees consider important in determining their health-related QOL.

Methods: We performed 4 focus groups in patients who had major lower extremity amputations resulting from CLI. They were conducted at 4 distinct centers across the United States to ensure broad geographic, socioeconomic, and ethnic representation.

Results: Of 26 patients (mean age, 64 years), 19 (73%) were Caucasian, 6 (23%) were African American, and 1 (4%) was Native American. Nearly, three-quarter of patients were men ($n = 19$, 73%) and had a high-school education or more ($n = 19$, 73%). Overall, 8 (31%) were double amputees and 17 (65%) had diabetes. Time since amputation varied across patients and ranged from 3 months to more than 27 years (mean, 4.3 years). Patients stated that their current QOL was determined by impaired mobility (65%), pain (60%), progression of disease in the remaining limb (55%), and depression/frustration (54%). Across 26 patients, more than half ($n = 16$, 62%) described multiple prior revascularization procedures. Although most felt that their physician did his/her best to salvage the affected leg (85%), a sizable minority would have preferred an amputation earlier in their CLI treatment course (27%). Furthermore, when asked how their care might have been improved, patients reported that facilitating peer support (88%), more extensive rehabilitation and prosthetist involvement (71%), earlier mention of amputation as a possible outcome (54%), and the early discontinuation of narcotics (54%) were potential areas of improvement.

Conclusions: Although QOL in vascular amputees seems primarily determined by mobility impairment, pain, and emotional perturbation, our focus groups identified that physician-controlled factors such as the timing of amputation, informed decision making, and postamputation support may also play an important role. The assessment of patient preferences regarding maintenance of mobility at the cost of increased pain versus relief of pain with amputation at a cost of diminished mobility is central to shared decision making in CLI treatment.

INTRODUCTION

Lower extremity amputation is a major morbid event, and its prevention has long been the foremost goal in critical limb ischemia (CLI) treatment, almost at all costs. Approximately, 1 million Americans suffer from CLI, and more than 150,000 new cases are diagnosed annually in the United

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[1]*Division of Vascular Surgery, University of Utah School of Medicine, Salt Lake City, UT.*

[2]*Section of Vascular Surgery, Dartmouth Medical School, Hanover, NH.*

[3]*Division of Vascular Surgery, Emory University School of Medicine, Atlanta, GA.*

[4]*Center for Survey Research, University of Massachusetts, Boston, MA.*

Correspondence to: Bjoern D. Suckow, MD, Division of Vascular Surgery, University of Utah Medical Center, 30 North 1900 East, Room 3C344, Salt Lake City, UT 84132, USA; E-mail: bjoern.suckow@hsc.utah.edu

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States.[1–3] Of these, about 20% will undergo major lower extremity amputation within 1 year of diagnosis,[4,5] whereas even higher amputation rates have been reported in certain high-risk patient subsets.[6–10] Although the number of endovascular and surgical interventions for CLI has dramatically increased over the last decade, trends suggest that the number of amputations in CLI patients is only modestly declining if not remaining constant.[11,12] Furthermore, amputation is greatly feared by patients,[13] and the incidence of limb loss (or conversely—limb salvage) has been incorporated into society-endorsed outcome guidelines as an important measure of lower extremity revascularization quality and performance.[14–16]

However, recent reports suggest that in light of patient-centered outcomes such as functional status and quality of life (QOL), a certain subset of CLI patients may have equivalent results with a primary amputation as opposed to aggressive revascularization strategies.[17,18] Although some have investigated a more focused measure of functional status and ''mobility success,''[19,20] a broad but disease-specific QOL measure for CLI patients is not available. Traditional QOL scores used in lower extremity peripheral vascular disease, such as the VascuQol and the PAVK-86, were derived and validated primarily in patients with claudication and may not be generalizable to patients with CLI.[21–23] Furthermore, broad QOL tools, such as the SF-36, the EuroQoL EQ-5d, and the Nottingham Health Profile,[24–26] are generic measures and are unable to adequately detect changes in emotion, mental health, or social functioning of patients with worsening limb ischemia.[22,27] Therefore, a more precise way to describe QOL in patients with CLI and amputation needs to be defined.

To better understand what domains determine QOL in vascular amputees from CLI, we conducted focus groups with an ethnically, geographically, and socioeconomically diverse patient cohort. We hoped to gain better insight into how CLI patients at the far end of the disease spectrum define their health-related QOL and thus to learn how physicians might incorporate shared decision making with patients in the CLI treatment process.

METHODS

Patient Selection

To be considered for focus group participation, patients had to have undergone at least one major lower extremity amputation (above or below knee) because of either ischemic rest pain and/or ischemic tissue loss. We did not establish exclusive parameters around the length of time since amputation, the number of limb salvage attempts patients had before amputation, or current functional status. Eligible participants had to be able to read and speak fluently in English and be at least 18 years old. They could be of either sex and of any race, and we did not discriminate on the basis of educational background.

Focus group participants were recruited at 4 different institutions: University of Utah Hospital (U of U), Salt Lake City Veterans Administration Hospital (SLC VA), Dartmouth-Hitchcock Medical Center (DHMC), and Emory University Hospital (Emory). Recruitment was performed via posted flyers or by personal invitation of eligible patients by staff in the cardiovascular, vascular surgery, and rehabilitation clinics at these institutions. The medical records of all eligible patients were reviewed to confirm the indication for amputation. A personal telephone invitation was then extended followed by a mailed letter explaining the details, risks, and benefits of the scheduled focus group session. The Institutional Review Board evaluated and approved this study at each institution.

Focus Groups

A total of 4 individual focus group sessions were scheduled and conducted with 1 group at each of the 4 participating institutions. Sessions were moderated by trained personnel from the Center for Survey Research (CSR) at the University of Massachusetts, Boston, or from the University of Utah Center for Clinical and Translational Science. Physicians and clinical personnel were intentionally excluded from focus group leadership during the sessions, to avoid bias in participant responses. To ensure that all groups were conducted in a uniform fashion, we developed and used a scripted moderator's guide to pose open-ended questions that encompassed a broad spectrum of QOL domains, allowing participants to freely describe their opinions. An abbreviated version of the questions asked of the participants via the moderator's guide is presented in Table I.

The focus groups were conducted in a nonclinic environment. They were video and audio recorded for analysis and comparison. Sessions were closed to nonparticipants and lasted no more than 2 hr each. At the beginning of the focus groups, written informed consent was obtained from each