

Living with Lower-Limb Prosthesis: Protocol for a Scoping Review of Qualitative Literature

Authors:

Mayank Rehani¹, Christine Guptill², Sandra Campbell³, and Jacqueline S. Hebert^{1,4}

Affiliation(s):

¹ Division of Physical Medicine & Rehabilitation, Department of Medicine, Faculty of Medicine & Dentistry, University of Alberta, Edmonton, Alberta, Canada

² School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa, Ottawa, Ontario, Canada

³ Health Sciences Unit, University of Alberta Libraries, University of Alberta, Edmonton, Alberta, Canada

⁴ Glenrose Rehabilitation Hospital, Edmonton, Alberta, Canada

Introduction

Amputation of the lower limb is a life-altering event with short- and long-term effects on a person's mobility and participation in activities of daily living. There are several causes for lower-limb amputation. In higher-income countries, peripheral vascular diseases and diabetes are commonly reported as the leading causes of limb amputation.¹⁻³ However, trauma has been reported as the leading cause in low- and middle-income countries.⁴⁻⁶ In 2017, an estimated 28.9 million people were living worldwide with unilateral lower-limb amputation and an additional 6.4 million people with bilateral lower-limb amputation due to traumatic causes.⁷ The types of services available to persons with amputation, their experience of healthcare, and their quality of life varies greatly depending on several factors including where they live, their age, and their access to services.

After amputation of the lower limb, the contemporary conventional method of attaching a prosthetic device is through a custom-designed socket. The residual limb is held in a socket to

which other prosthetic components are attached. In the last three decades, bone-anchored or osseointegrated prostheses have made a huge technological leap. Osseointegration involves inserting a titanium implant into the bone of the residual limb to which other prosthetic components are attached, bypassing the need for a socket. As noted thus far, the prevalence and etiology of lower-limb amputation, and the way in which lower-limb prosthetic devices are attached to the body, vary greatly.

Variability also exists in how health outcomes are assessed in lower-limb prosthesis users. There are a large number of measures to evaluate outcomes, but there is no gold standard.⁸ Such variability also exists in the assessment of quality of life in this population. Persons with amputation may report a reduction in their quality of life immediately after limb loss, but over time the response may change depending on their adaptation to the new condition.⁹ Most research examining the quality of life of persons with amputation is based on quantitative methods, and focuses on the use of the prosthesis and the satisfaction of the prosthesis user. Quantitative studies on quality of life and functionality after lower-limb amputations often use generic instruments such as SF-36 or EQ-5D or condition-specific measures such as Questionnaire for Persons with a Transfemoral Amputation (Q-TFA) or Trinity Amputation and Prosthesis Experience Scale-Revised (TAPES-R).¹⁰ Some of these outcome measures are not designed to capture the specific aspects of health that affect persons with lower-limb amputation, some only focus on a particular level of lower-limb amputation, while others are limited to a few domains of quality of life. Overall, the focus of quantitative outcome measures is on the objective measurement of health experiences that extends only as far as the domains they measure.

However, the nature of health experiences is subjective. A previous systematic review highlighted the need for higher quality research studies that examine the effectiveness of different prostheses and how they impact the users' daily living and quality of life.¹¹ While a comprehensive review of the quality of life in of this population using quantitative outcome measures is a worthwhile—albeit challenging—endeavour due to the variety of factors,¹² it may still not be sufficient to elucidate the experience of those living with a prosthetic device. Investigations associated with psychosocial aspects of persons with limb amputation have gained prominence in the literature in the last 20 years.⁸ *Psychoprosthetics* or “prosthesis-related

psychology” is a step in that direction and is often defined as the study of the psychological, social, and behavioral aspects of persons with amputation and the associated rehabilitation process.

Technological interventions in prosthetics for the lower limb have made tremendous progress in the last few decades. However, understanding the lived experience of those for whom these interventions are designed is crucial and can have a humanizing influence on the research and development process by including the patients’ voices. Conventionally, understanding lived experience falls within the purview of qualitative research methods. Through qualitative research studies, we can learn directly from patients about their experiences, perceptions, and points of view. Qualitative literature has the potential to inform, instruct, and inspire the reader. Clinicians informed by the patients’ experience can be more effective and improve the care that they provide. Researchers informed by the patient’s perspective can study health-related outcomes that are reported to be relevant by this population. Developers of technological solutions can be sensitized to the conditions of everyday living that the user of their technology experience. A scoping review of qualitative research studies can serve as a compendium of the lived experiences of many individuals and meet this need.

The overall goal of this scoping review is to provide clinicians, researchers, and developers of prosthetic technologies with a broader understanding of the experience and perspectives of persons with amputation on their quality of life, challenges, successes, adaptations, their psychosocial status and needs, and the barriers and facilitating factors to the adoption of their prosthetic devices. This may promote a deeper understanding and appreciation for the lived experience of prosthesis users, and the development of patient-centered interventions or solutions by addressing some aspects of the psychosocial determinants of health that impact their overall quality of life.

The specific aims of this scoping review are threefold. First, to determine the extent to which lived experience of lower-limb prostheses users has been examined through the use of qualitative research designs. Second, to summarize the research findings and present similarities and differences in the lived experiences in various contexts to elucidate the phenomenon. Third, to identify gaps in the existing literature and highlight potential areas for future research. This scoping review will follow the PRISMA-ScR statement and checklist.¹³

Inclusion Criteria

Participants

This scoping review will consider qualitative research with participants (aged 18 and older) with an acquired lower-limb amputation (any level) who use any type of prosthetic device. This may include socket-suspended, bone-anchored, or other types of prostheses.

Concept

The broad concept examined by this scoping review of qualitative research literature is the lived experience of adults (civilians or military personnel) who use a prosthetic device following an acquired lower-limb amputation. Their perceptions of quality of life, functional abilities, opportunities, challenges, and psychosocial aspects will be explored.

Context

Literature from a variety of contexts (rural/urban or developed/developing countries) will be considered to understand the contexts within which the lived experience of persons with amputation has been studied. Articles which are primarily based on clinician perspectives on the quality of life of persons with amputation will not be included. If an article also focusses on the perspectives of the individuals with amputation, that portion will be included.

Types of Evidence Sources

This scoping review will consider literature that uses any qualitative research methodology to elaborate on the phenomenon of living with a lower-limb prosthetic device following an amputation. Previous review articles (such as, but not restricted to, literature review, qualitative systematic review, qualitative metasynthesis) on this topic will also be considered.

Methods

Search Strategy

This scoping review will consider primary research articles and grey literature (peer-reviewed scientific abstracts/academic conference presentations); however, it will not include

opinion pieces in non-peer reviewed journals. The search strategy will be developed by two reviewers (MR and SC).

An initial limited search of two databases (MEDLINE and PsycInfo) will be undertaken to get a preliminary idea of the kind of literature available on this topic, followed by analysis of the text words contained in the titles and abstracts, and of the index terms used to describe these articles. Next, the search strategy will be executed and all databases will be searched using the identified keywords and index terms. Individual search strategies will be adapted and modified for each database, as necessary. This search will be executed by an expert searcher/health librarian (SC). Thirdly, the reference lists of the articles that have been selected for full-text or included in this review will be searched for additional sources. If a non-English article is included at the title and abstract screening stage, its authors will be contacted to inquire if the article is available in English. Authors of primary sources may be contacted for more information or to determine if there are additional sources that should be considered for inclusion.

A complete search strategy for MEDLINE (one of the major databases) is included as an appendix to this protocol. Only literature published on or before the date of the search be included. As such, the start date of the search will not be limited and the end date of the search will be the date when the search will be conducted. The search will be detailed in a PRISMA diagram.

The following databases will be searched: MEDLINE, Embase, PsycInfo, CINAHL, Scopus, Global Health, PEDro, Prospero, Cochrane, ProQuest Dissertations, and Google Scholar. Databases will be searched using relevant search syntaxes and combining key MeSH and other database-specific subject terms together with commonly used keywords.

Duplicates will be removed and the final search results will be uploaded to Covidence.¹⁴ Two independent reviewers (MR and CG) will screen the search results initially based on the title and abstract. If there are any disagreements at this stage, the search result will be included for full-text review to decide on its inclusion. Full-text review will be conducted by the two reviewers (MR and CG) following which a final decision to include/exclude will be made. Where consensus has not been attained, a third reviewer (JH) will serve as arbiter.

An initial search has been carried out in MEDLINE (an initial search strategy for MEDLINE can be found in Appendix 1). A review of the text words found in titles and abstracts of the retrieved articles and of the index terms in the databases used to describe these articles has been undertaken. This will serve to refine the final search strategy by incorporating the key words and tailored index terms found for each database.

Data extraction

Data extraction will include information regarding the population and concept relevant to the aim of this scoping review. The data extracted will be general study characteristics (such as year of publication and location (country) of the study, urban/rural context), the specific aims/purpose of the study, participant information (such as number, age range, and sex ratio of the participants), data collection methods, type of prosthesis, and key findings (themes and conclusions) that are relevant to the objectives of this scoping review.

Data extraction will be piloted between two reviewers (MR and CG) on at least 2 included articles to ensure all relevant results are extracted. Following this the data from the remaining included articles will be extracted by only one reviewer (MR).

The data extraction tool will be revised as necessary throughout the data extraction process. Any deviations from the protocol will be documented in the final scoping review.

Data Analysis

Upon extracting data from included articles, we will collate information based on type of qualitative research method used and context. We will provide a descriptive summary of the common themes that elucidate the phenomenon of living with a lower-limb prosthesis. Similarities and nuances in the reported themes will be noted and discussed.

Data Presentation

Data will be compiled in a tabular format. These will be used to identify, characterize, and summarize the evidence and identify any gaps in research. Tables will categorize data by conceptual categories including context, type of prosthesis, study aim, and key findings. A world

map noting the countries and contexts within which this topic is studied will also be presented. These will be described to ensure that data is organized and comparable. Perceived gaps in literature will also be discussed.

References

1. Ahmad N, Thomas GN, Gill P, Chan C, Torella F. Lower limb amputation in England: prevalence, regional variation and relationship with revascularisation, deprivation and risk factors. A retrospective review of hospital data. *J R Soc Med* [Internet]. 2014 Nov 11;107(12):483–9. Available from: <https://doi.org/10.1177/0141076814557301>
2. Imam B, Miller WC, Finlayson HC, Eng JJ, Jarus T. Incidence of lower limb amputation in Canada. *Can J Public Heal* [Internet]. 2017;108(4):374–80. Available from: <https://doi.org/10.17269/CJPH.108.6093>
3. Behrendt C-A, Sigvant B, Szeberin Z, Beiles B, Eldrup N, Thomson IA, et al. International Variations in Amputation Practice: A VASCUNET Report. *Eur J Vasc Endovasc Surg Off J Eur Soc Vasc Surg*. 2018 Sep;56(3):391–9.
4. Moini M, Rasouli MR, Khaji A, Farshidfar F, Heidari P. Patterns of extremity traumas leading to amputation in Iran: results of Iranian National Trauma Project. *Chinese J Traumatol = Zhonghua chuang shang za zhi*. 2009 Apr;12(2):77–80.
5. Rouhani A, Mohajerzadeh S. An epidemiological and etiological report on lower extremity amputation in northwest of iran. *Arch bone Jt Surg*. 2013 Dec;1(2):103–6.
6. Shaw J, Challa S, Conway D, Liu M, Haonga B, Eliezer E, et al. Quality of life and complications in lower limb amputees in Tanzania: results from a pilot study. *Lancet Glob Heal* [Internet]. 2018;6:S18. Available from: <https://www.sciencedirect.com/science/article/pii/S2214109X18301475>
7. McDonald CL, Westcott-McCoy S, Weaver MR, Haagsma J, Kartin D. Global prevalence of traumatic non-fatal limb amputation. *Prosthet Orthot Int* [Internet]. 2020 Dec 4;0309364620972258. Available from: <https://doi.org/10.1177/0309364620972258>
8. MATOS DR, NAVES JF, ARAUJO TCCF de. Quality of life of patients with lower limb amputation with prostheses. *Estud Psicol* [Internet]. 2020 Dec 2 [cited 2021 Jun 23];37. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-166X2020000101002&tlng=en
9. Asano M, Rushton P, Miller WC, Deathe BA. Predictors of quality of life among individuals who have a lower limb amputation. *Prosthet Orthot Int* [Internet]. 2008 Jan 1;32(2):231–43. Available from: <https://doi.org/10.1080/03093640802024955>
10. Desmond D, Gallagher P. Quality of Life in People with Lower-Limb Amputation BT - Handbook of Disease Burdens and Quality of Life Measures. In: Preedy VR, Watson RR, editors. New York, NY: Springer New York; 2010. p. 3785–96. Available from: https://doi.org/10.1007/978-0-387-78665-0_219
11. Samuelsson KAM, Töytäri O, Salminen A-L, Brandt Å. Effects of lower limb prosthesis on activity, participation, and quality of life: a systematic review. *Prosthet Orthot Int* [Internet]. 2012 Feb 3;36(2):145–58. Available from: <https://doi.org/10.1177/0309364611432794>
12. Suckow BD, Goodney PP, Nolan BW, Veeraswamy RK, Gallagher P, Cronenwett JL, et

- al. Domains that Determine Quality of Life in Vascular Amputees. *Ann Vasc Surg*. 2015;29(4):722–30.
13. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* [Internet]. 2018 Sep 4;169(7):467–73. Available from: <https://doi.org/10.7326/M18-0850>
 14. Veritas Health Innovation. Covidence systematic review software [Internet]. Melbourne, Australia; Available from: www.covidence.org

Appendix 1

Ovid MEDLINE(R) ALL <1946 to June 8, 2021>

#	Search Statement	Results
1	(exp Artificial Limbs/ or (prosth* or artificial).mp.) and (lower extremity/ or ankle/ or exp foot/ or knee/ or leg/ or thigh/)	9219
2	((prosth* or artificial) adj3 (lower extremit* or "lower limb*" or leg or legs or ankle* or foot or feet or "thigh*or transfemora*" or "trans-femora*" or "transtibia*" or "trans-tibia*")).mp.	2378
3	exp Artificial Limbs/ and ("lower extremit*" or "lower limb*" or ankle or ankles or foot or feet or knee or knees or leg or legs or thigh* or "transfemora*" or "trans-femora*" or "transtibia*" or "trans-tibia*").mp.	3955
4	1 or 2 or 3	11466
5	(qualitative or ethno* or ethnog* or ethnonurs* or emic or etic or leininger or noblit or "field note*" or "field record*" or fieldnote* or "field stud*" or "participant observ*" or "participant observation*" or hermeneutic* or phenomenolog* or "lived experience*" or heidegger* or husserl* or "merleau-pont*" or colaizzi or giorgi or ricoeur or spiegelberg or "van kaam" or "van manen" or "grounded theory" or "constant compar*" or "theoretical sampl*" or (glaser and strauss) or "content analy*" or "thematic analy*" or narrative* or "unstructured categor*" or "structured categor*" or "unstructured interview*" or "semi-structured interview*" or "maximum variation*" or snowball or audio* or tape* or video* or metasynthes* or "meta-synthes*" or metasummar* or "meta-summar*" or metastud* or "meta-stud*" or "meta-ethnograph*" or metaethnog* or "meta-narrative*" or metanarrat* or " meta-interpretation*" or metainterpret* or "qualitative meta-analy*" or "qualitative metaanaly*" or "qualitative metanaly*" or "purposive sampl*" or "action research" or "focus group*" or photovoice or "photo voice" or "mixed method*").mp. or exp qualitative research/	890713
6	"treatment adherence and compliance"/ or exp "patient acceptance of health care"/ or exp patient satisfaction/ or exp "Quality of Life"/	441010

7	("quality of life" or qol or hrqol or satisf* or dissatisf* or functionality or psychosocial or psycholog* or social or socioeconomic* or economic* or aesthetic* or cosmetic* or "stump pain" or "peer support*" or financial* or emotion* or comfort* or wearability or "body image" or "self image" or usability or acceptance or barrier* or facilitator* or motivator* or compliance or "day to day" or "daily use" or experien*).mp.	4743178
8	6 or 7	4765407
9	4 and 5 and 8	153
10	9 not ((knee or hip) adj3 arthroplast*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	146