Published in final edited form as:

Prosthet Orthot Int. 2023 February 01; 47(1): 26–42. doi:10.1097/PXR.0000000000000142.

Improving shared decision-making for prosthetic care: a qualitative needs assessment of prosthetists and new lower-limb prosthesis users

Chelsey B. Anderson[1,2], **Stefania Fatone**[3], **Mark M. Mañago**[1,2], **Laura A. Swink**[1,2], **Emily R. Hager**[1,2], **Andrew J. Kittelson**[4], **Cory L. Christiansen**[1,2], **Dawn M. Magnusson**[1]

[1]Department of Physical Medicine and Rehabilitation, Physical Therapy Program, University of Colorado, Aurora, CO, USA

[2]Department of Research, Geriatric Research, Education, and Clinical Center, VA Eastern Colorado Healthcare System, Aurora, CO, USA

[3]Department of Rehabilitation Medicine, Division of Prosthetics and Orthotics, University of Washington, Seattle, WA, USA

[4]Department of Physical Therapy and Rehabilitation Science, University of Montana, Missoula, MT, USA

Abstract

Background: Prosthesis design is complex and multiple appropriate options exist for any individual with lower-limb amputation. However, there is insufficient evidence for guiding decision-making. Shared decision-making (SDM) offers an opportunity to incorporate patient-specific values and preferences where evidence is lacking for prosthesis design decisions. To develop resources to facilitate SDM, and consistent with the International Patient Decision Aid Standards, it is necessary to identify the decisional needs of prosthetists and prosthesis users for prosthesis design decisions.

Objectives: To assess the needs of prosthetists and new prosthesis users for SDM about the first prosthesis design.

Study design: Qualitative descriptive design.

Corresponding author: Chelsey B. Anderson, University of Colorado, Anschutz Medical Campus, Mail Stop C244, 13121 E. 17th Avenue, Aurora, CO 80045. Chelsey.anderson@cuanschutz.edu.

Author contributions

The authors disclosed the following roles as contributors to this article: C.B.A. assisted in manuscript conceptualization, investigation, writing (original draft preparation, review, and editing), funding acquisition, data curation and formal analysis, and validation. S.F. assisted in manuscript conceptualization, supervision, and writing review and editing. M.M.M. assisted in manuscript conceptualization, supervision, and writing review and editing. L.A.S. assisted in manuscript editing, formal analysis, validation, supervision, and writing review. E.R.H. assisted in manuscript writing review and editing, and formal analysis. A.J K. assisted in manuscript conceptualization, supervision, and writing review and editing. C.L.C. assisted in manuscript conceptualization, supervision, and writing review and editing. D.M.M. assisted in manuscript conceptualization, data curation, formal analysis, and writing review and editing, supervision, and validation.

Declaration of conflicting interest

The author disclosed no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Supplemental Digital Content

There is no supplemental material in this article.

Methods: Six focus groups were conducted with 38 prosthetists. Individual semistructured interviews were conducted with 17 new prosthesis users. Transcripts were analyzed using directed content analysis, with codes defined a priori using existing frameworks for SDM: the Three Talk Model for SDM and the Ottawa Decision Support Framework.

Results: Four main themes were identified among prosthetists and prosthesis users: acknowledging complexity in communication, clarifying values, recognizing the role of experience to inform preferences, and understanding the prosthetic journey.

Conclusions: Resources that support SDM for the first prosthesis design should consider methods for identifying individual communication needs, support with clarifying values, and resources such as experience for achieving informed preferences, within the context of the overall course of rehabilitation and recovery following lower-limb amputation. The themes identified in this work can inform SDM to promote collaborative discussion between prosthetists and new prosthesis users when making prosthesis design decisions.

Keywords

amputation; physical and rehabilitation medicine; rehabilitation; decision support techniques; prostheses; prosthesis design; prosthesis fitting; qualitative research; shared decision-making; lower-limb amputation

Background

Rehabilitation after lower-limb amputation (LLA) is complex, and typically involves design, provision, and training to use a prosthesis to restore physical function and achieve rehabilitation goals.[1,2] Specific to prosthesis design, decisions center on choosing appropriate modular parts of a prosthesis, including the socket, suspension, interface, and distal components, for a given person with LLA.[3] Prosthetic components may include custom parts made uniquely to fit the residual limb, such as a total surface bearing or patellar tendon bearing socket style for a transtibial amputation, or the selection of ready-made parts such as the make, model, and appearance of a prosthetic foot.[3] Such options may differ in comfort, appearance, method of use, and function, underscoring the individualized nature of prosthesis design decision-making.[4] Furthermore, available options within all parts of a prosthesis have increased in number and complexity over the past several years. For example, more than 100 prosthetic foot options are available in today’s commercial market.[5,6] This can be a problem, because evidence to support choosing one option over another is limited, complicating the prosthesis design process.[3,5] In addition, many people with LLA express feeling underinformed about prosthetics[7] and uncertain about how to participate in prosthesis design decisions,[8] despite their desire to engage in the decision-making process.[8] Given these challenges in prosthesis design decision-making for an individual, it is essential to incorporate unique patient values and needs into prosthesis design decisions after LLA.[4]

Shared decision-making (SDM) is a process whereby clinicians and patients exchange information about available options to make informed decisions that reflect patients’ personal goals and values.[9–11] SDM is especially valuable in situations of medical uncertainty, where evidence is insufficient, and/or when personal preferences may heavily influence a decision.[12] Rehabilitation settings in particular offer several opportunities for incorporating SDM, such as with goal setting, adherence to treatment and therapy plans, and promoting patient autonomy.[13–16] Therefore, it is not surprising that recent clinical practice guidelines for lower-limb prosthetic rehabilitation recommend incorporating SDM in treatment decisions to improve health outcomes.[13] The potential of SDM to maximize the health of prosthesis users is made more promising by the long-term relationship between prosthesis users and prosthetists and the changing needs of prosthesis users throughout their life span. Although a patient decision aid for people undergoing partial foot amputation has been described,[17] SDM has yet to be realized in rehabilitation care for people with LLA, as there are several challenges and barriers to use of SDM in routine practice. SDM may require communication and cultural changes in prosthetic care,[11] and the complex health presentations of people with LLA may increase challenges for SDM. Thus, both people with LLA and prosthetists would benefit from resources that support incorporating SDM into prosthesis design decisions.

Shared decision aids (SDAs) are resources designed to support SDM by helping individuals engage in health care decisions through personalized information on available options, assistance with identifying and communicating values, and weighing of options and associated outcomes for making a given health decision.[11,18] The International Patient Decision Aid Standards (IPDAS) were proposed to provide a systematic approach for developing SDAs across various health care settings, and includes steps of 1) evaluating the decisional needs of stakeholders involved in a given health decision, 2) forming a stakeholder group to guide development of the SDA prototype, 3) alpha testing of the SDA with the stakeholder group, and 4) beta testing in real-life settings with target patients and clinicians.[18,19] Qualitative methods are ideal for exploring a phenomenon and its influencing variables in depth (e.g. the decisional needs inquiry described in IPDAS step 1).[20] To develop a SDA for prosthesis design, the aim of this study centered on the first step of the IPDAS process, and focused on assessing the decisional needs of prosthetists and new prosthesis users regarding the design of the first prosthesis. Because prosthesis design decisions typically begin with the first prosthesis when people are least knowledgeable about the prosthetic rehabilitation process, and influence later prostheses,[21] the focus of this study was on the needs of new prosthesis users and their prosthetists for the first prosthesis design.

Methods

Study design

We leveraged two frameworks on the process of SDM and decisional needs for SDM (the Three Talk Model for SDM and the Ottawa Decision Support Framework, Table 1),[22–24] to inform the directed content analysis approach to identify themes as they relate to SDM.[25] The Three Talk Model for SDM is a framework for conducting SDM in clinical practice, through steps of deliberation, team talk, option talk, decision talk, decision support, initial preferences, and informed preferences.[22,23] The Ottawa Decision Support Framework is a framework that outlines the support needed by patients and health care providers.[24] Semistructured focus groups were conducted with prosthetists to allow for expansion of ideas through group interaction.[26] A group format was deemed acceptable, as it was considered unlikely that personally sensitive topics would arise from inquiry into the prosthetist's decisional needs, given the professional nature of the decisions being made. By contrast, individual semistructured interviews were conducted with prosthesis users because of the sensitive and personal nature of values associated with prosthesis design decisions (e.g. thoughts on personal finances, personal views, social appearance, roles, and norms).[27,28] The Colorado Multiple Institutional Review Board approved study procedures.

Study participants

To develop a SDA that would meet the diverse needs of people with LLA, purposive sampling was used for both groups to capture perspectives from people with various demographic and clinical characteristics.[29] For prosthetists, purposive sampling aimed to vary the practice settings and years of experience practicing prosthetics, and for new prosthesis users, a diverse representation of amputation level and etiology, age, and sex. Prosthetist participants were included if they were 1) certified prosthetists, 2) actively providing prosthetic care for people with LLA for 1 or more years, and 3) English-speaking. Prosthetists were excluded if 1) they provided care outside the United States, or 2) were unable to participate in a 1-hour focus group. Prosthesis users were included if they 1) had a transtibial, knee disarticulation, or transfemoral lower-limb amputation, 2) were currently using or in the process of receiving their first definitive prosthesis, 3) were at least age 18 years or older, and 4) were English-speaking. Prosthesis users were excluded if they 1) had a history of using more than one prosthesis in the past (e.g. for a prior or contralateral limb amputation), or 2) were unable to participate in a 1-hour interview. Both groups excluded participants who provided or received care within the Department of Veteran's Affairs, given it is uniquely different in the delivery of prosthetic care from all other health care settings. Based on other qualitative work in SDM,[30] sampling aimed to recruit at least 14 prosthesis users to achieve data saturation, the point in qualitative analysis where no additional findings are identified.[31,32] Based on qualitative recommendations for focus groups, sampling aimed to recruit at least 4 focus groups of 5–6 prosthetists.[26,28]

Recruitment

A flyer and a letter describing the study aims were used to recruit both prosthetists and prosthesis users. Prosthetists were recruited via email through local and national professional partnerships, and through a national Orthotics and Prosthetics List Server. Prosthesis users were recruited through 1) referral of prosthetists who participated in the study, 2) the Amputee Coalition website, 3) a national Amputee List Server, and 4) local and national amputee peer support programs. One research team member screened all potential participants over the phone or via email. Recruitment for both focus groups and individual interviews extended for at least two additional sessions beyond data saturation.[31,32] All participants provided electronic written informed consent.

Data collection

After enrollment, all participants provided demographic information via an online survey. The prosthetists demographic survey included sex, race, ethnicity, credentials, and years of experience. The prosthesis users survey included sex, race, ethnicity, height, weight, time since amputation and prosthesis receipt, level and etiology of amputation, living status, employment, and education. A certified prosthetist trained in qualitative methods conducted all focus groups and interviews (CA). An iterative team approach was used to develop a semistructured interview guide and focus group discussion guide, focusing on concepts outlined in the two frameworks[22–24,33] (Table 2). Both guides included open-ended questions exploring the presentation of options for the first prosthesis design, pros and cons associated with those options, concepts of SDM, and key decisional needs.[22] For both focus groups and individual interviews, additional probing questions were used to further explore participant responses. All focus groups and individual interviews took place over the phone or video conference (Zoom Video Communications Inc, San Jose, CA, USA) and were audio-recorded and transcribed verbatim.

Data analysis

Prosthetist focus groups and prosthesis user interviews were professionally transcribed and managed with ATLAS.ti 9 (Scientific Software Development GmbH, Berlin, Germany), a software program for organizing large bodies of textual data for qualitative analysis. All data were analyzed using qualitative directed content analysis.[25,34] Analysis began during data collection through team debriefs and a review of field notes, and continued with repeated readings of transcripts to achieve data immersion. The research team coded all transcripts with codes outlined and defined a priori by the Three Talk Model for SDM,[22,23] and the Ottawa Decision Support Framework[24,33] (Table 1). Incorporating overarching domains from the Three Talk Model for SDM aimed at 1) clarifying the current state of SDM between prosthetists and prosthesis users in the prosthesis design process, 2) highlighting steps within SDM where decision support is indicated, and 3) providing initial insight into areas for supporting SDM. The Ottawa Decision Support Framework included three key elements: 1) identifying key determinants of prosthesis design decisions (e.g. knowledge, values, and support and resources), 2) providing decision support interventions, and 3) evaluating the success of decision support in improving the decision process and outcomes.[24]

To maintain intercoder reliability and manage potential biases, two members of the research team (one clinician and one nonclinician, C.A. and E.H., respectively) independently reviewed and coded the transcripts and reconciled results. Codes were modified or added as needed; any new codes that did not fit with existing codes were discussed to further extend or refine the existing codes.[25] Where disagreements arose, a third team member was consulted (D.M.). Codes were then grouped into themes to identify the primary components of prosthesis design decisions, key determinants for decisions, and decisional needs of both prosthetists and prosthesis users.

Data triangulation, member checking, coding rules, and an audit process were used to maintain unbiased results, research rigor, and trustworthiness of the findings.[34] Data triangulation involved a paper trail of investigator memos and participant transcripts. In addition, field notes were collected for each interview to support qualitative data interpretation, reflexivity, and to account for personal factors introduced by interviewers (e.g. identity and work role).[26] To ensure all ideas and constructs accurately represented each participant's point of view, the content of the interview or focus group was reviewed with participants immediately after each interview or focus group (i.e. member checking). Debriefing meetings between the interviewer and another investigator (L.S.) took place after every one to three interviews and throughout the coding process, to manage potential bias and coding rules, monitor for new constructs, data saturation, and areas for future probing.[35] To ensure credibility of findings, final results were reviewed with an expert working group of six experienced prosthesis users and five prosthetists not involved in the original interviews.

Results

Recruitment and data collection for prosthetists and prosthesis users took place between July 2020 and March 2021 (Table 3). Thirty-eight prosthetists participated in six focus groups (5–9 prosthetists per group, 74% male, range of experience 2–42 years, mean interview duration: 89 ± 11 minutes, range 74–105 minutes). Data saturation was achieved after the fourth focus group, with six total focus groups conducted. Individual prosthesis user interviews were conducted with a total of 17 people with LLA (53% male, 76% transtibial amputation, mean interview duration: 78 ± 16 minutes, range 54–122 minutes). Data saturation was achieved after the 11th interview, with 17 total interviews conducted.

The main decisional needs and opportunities for SDM for prosthesis design for prosthetists and new prosthesis users aligned under four key themes: 1) acknowledging complexity in communication, 2) clarifying values, 3) recognizing the role of experience to inform preferences, and 4) understanding the prosthetic journey (Table 4). The themes will be presented per the sequence of the stages of SDM, as depicted in the Three Talk Model.[23]

Acknowledging complexity in communication

Both prosthetists and prosthesis users discussed challenges with information exchange about prosthesis design. Prosthetists expressed concern about overwhelming new prosthesis users with too much information during initial interactions. The wide variety of options, complexity of information, and lack of experience with using a prosthesis in daily life acted as barriers for meaningful information exchange about prosthesis design options:

> "Sometimes, especially in the beginning, patients tend to be very overwhelmed bythis kind of alien experience. There is no ground zero and they don't know...what small things factor in."—prosthetist 1

Consistent with prosthetists' concerns, new prosthesis users described feelings of being overwhelmed during initial interactions with their prosthetist. In addition to learning about prosthetics, they were working through challenges with recovery after amputation, managing health, limb loss, and adapting to life as a person with amputation. Although most new prosthesis users desired awareness of prosthesis design options and anticipated decision points, they acknowledged challenges in receiving sufficient information without being overwhelmed:

> "It was like an information overload honestly."—prosthesis user 13

Both prosthetists and new prosthesis users discussed a need to disseminate information over time to allow for deliberation:

> "The one other critical thing I feel is important and that has helped is, if possible, spreading these evaluation appointments and consultation appointments over a period and over multiple appointments... rather than bombarding them with all the information in one appointment or doing one assessment, it's a lot to take in for them, "—prosthetist 37

New prosthesis users also emphasized the importance of identifying their personal communication needs for information and working with their prosthetists, and acknowledged how each individual with a new amputation may have different needs:

> "I think that's really significant to know what kind of person you are. If you really want a lot of information, then a prosthetist needs to be different."—prosthesis user 17

Within the Three Talk Model for SDM, clarifying choice and discussing decision options are crucial for SDM. Overall, prosthetists described the complexity of communicating prosthesis design decisions, and difficulty with gauging individual receptiveness to information (e.g. what, how much, and when to provide). New prosthesis users recognized their desire to participate in meaningful discussion about prosthesis design, but expressed concerns about the abundance of information and their lack of knowledge needed to participate in early prosthesis design decisions. Both prosthetists and prosthesis users felt that information exchange on prosthesis design options should be adjusted to the communication needs of each individual user, with time for consideration.

Clarifying values

Both prosthetists and new prosthesis users indicated the need for identifying prosthesis users' personal values associated with prosthesis design (Table 4). Prosthetists emphasized the importance of interviewing new prosthesis users on their lifestyle and goals for using a prosthesis, to inform optimal prosthesis design (e.g. selecting a foot component for prioritizing high activity vs. stability). However, prosthetists described challenges with gauging a new prosthesis user's lifestyle and goals beyond basic functions:

> "I think they [new prosthesis users] have goals in their head. They just often don't express them past walking because that's their immediate—that's the main thing that's blocking them right now is walking', so that they can get back to cooking or grocery shopping or every other part of life... I think that most of my patients want to get back to life prior to amputation and they just don't verbalize that or don't say all of the stuff that they were doing. I get a lot of 'I want to be able to walk again' and then 'that's the extent of my goals.'" - prosthetist 12

Personal values associated with prosthesis design also influenced decision-making for new prosthesis users. New prosthesis users described personal values that included appearance, postural control (i.e. balance), use of the prosthesis with clothing and shoes, health, and life participation goals (e.g. caring for young children, or playing golf). Ultimately, new prosthesis users expressed a desire to learn about prosthesis design options as they relate to their personal values and goals:

> “I just want to know my personal life options‖I think that we all just want to know what personally is going to be good for my preference, for what I want to do.”—prosthesis user 8

To engage in SDM about prosthesis design, both prosthetists and new prosthesis users described the need for considering values before working on the first prosthesis design:

> “...even if there was something that could give them ideas of what’s important to you or what activities, so that when you come to the office, you already have some kind of all those ideas sitting in your head. So that, now, you didn’t put them on the spot.”—prosthetist 15

> “...you need to sit down and write down what’s important in your life, or at least think about what’s important in your life and what you want out of your life after amputation occurs...honestly, I think it would be helpful because you know exactly what you want out of your goals and your life. And so, it’s going to make it a whole lot easier to weigh the pros and cons of different options knowing what you want.”—prosthesis user 3

SDM involves identifying and incorporating an individual’s values into the decision, through a process of deliberation. However, both groups ultimately described challenges with identifying and eliciting high-quality conversation around personal values, and recognized a need for considering personal values before initiating discussion of prosthesis design options.

Recognizing the role of experience to inform preferences

Prosthesis users and prosthetists described various techniques that assisted new prosthesis users in achieving informed preferences, including pictures, show and tell, demonstration, trialing use of prosthetic components (e.g. feet and knees), and peer sharing of personal experience with a given option:

> “I think a good starting point is by showing patients either pictures or actual prosthesis and demonstrating the whole suspension mechanism. I think that’s a good starting point. I don’t think we can reach a level where the patient can completely make a decision. But I think just giving them—just helping them understand what the process entails. I think we can get good feedback from the patient and that might help us make that decision better. ”—prosthetist 37

Prosthetists and prosthesis users both described physical exposure and/or physical experience using different prosthesis design options to be ideal for informing preferences:

> “...trying them [prosthetic foot options] on and actually feeling and seeing the difference in between how walking up and down hills. That was the big one [for decision-making]. Slopes were just like, mind boggling.”—prosthesis user 13

> "It'd be really nice if there was some way to reimburse for some particular trial error situations where it is, you know, because once you put a liner on somebody, you can't really use that again."—prosthetist 27

Achieving informed preferences is one goal within the Three Talk Model for SDM. In order for new prosthesis users to achieve informed preferences, both prosthetists and prosthesis users recognized the need for experience using prosthesis design options. Although alternatives for achieving preferences were identified, the lack of physical experience with using a prosthesis was acknowledged as a barrier for new prosthesis users. Ultimately, new prosthesis users expressed a desire for resources and information on achieving informed preferences for a given prosthesis design option to support deliberation.

Understanding the prosthetic journey

Both prosthetists and prosthesis users emphasized a need for understanding the prosthetic rehabilitation process to participate in prosthesis design decisions. For the first prosthesis, a new prosthesis user will often go through rehabilitation and therapy (e.g. gait training to gain strength and balance) with an interim prosthesis. Such prosthesis training typically requires prosthesis users to undergo one or more socket replacements to accommodate limb maturation. The need for prosthesis changes at these various time points may introduce an opportunity to modify prosthesis design decisions, such as interface or suspension options. Prosthetists discussed the potential for changing prosthesis design to accommodate a new prosthesis user's evolving needs and preferences:

> "A conversation that I had with all brand new amputees is when we were making this leg for you, it's for your abilities and capabilities that we're anticipating in the next six months at the snapshot in time, and what is appropriate for you today, may not be appropriate for you in the short term."—prosthetist 19

By contrast, many new prosthesis users described the process of socket replacement as unexpected, and were uncertain about what parts of their prosthesis could be changed at each point:

> "I wasn't expecting for me to have to get so many sockets. I didn't know that I have to get this replaced so many times. "—prosthesis user 8

When the prosthetic rehabilitation process was clarified, new prosthesis users recognized the benefits of understanding the key decisions for initial and future prosthesis design:

> "I think the biggest thing is, make sure you just lay out all the options on the table and then, explaining that it's a process, especially because it's so common. I mean, it's very common that you're going to go through a couple of sockets in the first year."—prosthesis user 13

A new prosthesis user's awareness of the process for changing and adjusting their first prosthesis was helpful for exploring prosthesis design options and anticipating potential future decision points. New prosthesis users in particular emphasized a need for support in understanding the process and future decision points:

> "It was a short time afterward where I was learning about other different options and wondering, you know, is this going to be my next option, and then...To understand the progression was important to me."—prosthesis user 17

Clarifying choice within the Three Talk Model for SDM involves ensuring patient awareness of a decision and that options are available. However, new prosthesis users emphasized their uncertainty about immediate and future decision points for their first prosthesis (e.g. prosthetic socket, suspension, interface, and/or components). Both prosthetists and prosthesis users acknowledged the importance of awareness of the prosthetic rehabilitation process for supporting new prosthesis users to participate in prosthesis design decisions.

Discussion

This study offers insight into the needs of prosthetists and new prosthesis users for SDM during the first prosthesis design, and corresponding strategies for supporting SDM (Table 5). Four key themes were identified: 1) acknowledging complexity in communication, 2) clarifying values, 3) recognizing the role of experience to inform preferences, and 4) understanding the prosthetic journey. The themes identified in this work may inform decisional needs and strategies for supporting SDM.

The results from this work recognize the complexity in communication needs for information associated with prosthesis componentry and the various available options. Variability in componentry remains a challenge in prosthetic care, given that clear communication of the decision and options is essential in the Three Talk Model for SDM.[22,23] In the case of prosthesis design, communication about decisions involves clarifying the decision type (consistent with the Ottawa Decision Support Framework), and introducing information on the separate choices for the parts of a prosthesis (e.g. suspension, socket, interface, and knee and foot components), before introducing potential options within each choice. The multiple choices within prosthesis design complicate SDM, compared with where SDM is used to inform discrete decisions with a finite list of options.

Both prosthetists and new prosthesis users in this study expressed concerns about overwhelming new prosthesis users with complex information. Early after limb loss, it is not uncommon for new prosthesis users to grapple with managing physical, social, and emotional burdens in addition to managing their rehabilitation; with the first prosthesis, understanding prosthesis design choices and options may not be a priority, and individual needs for information are mutable.[36] Both SDM models suggest that information provision should be unbiased, accessible, and tailored to each individual, and that health care providers must also ensure that the information is received and understood by patients.[22,37] Although complex health information may contribute to an individual patient's decision uncertainty and cognitive overload, tailoring information sharing at the individual level and ensuring patient understanding offers an opportunity to strengthen the partnership between health care providers and patients in support of patient autonomy.[38] Relaying the complexities of information around prosthesis design to each new prosthesis user is especially challenging in prosthetic care, and it must be recognized that a health care provider's interpretation of a patients' desires and values for information is prone to inaccuracy.[39,40]

In the interest of informing SDM for prosthesis design, the results from this work demonstrate the importance of identifying communication needs and the decisional need for matching approaches for information exchange between prosthetists and new prosthesis users. The study results also acknowledge the necessity of time for new prosthesis users to process information. Therefore, future SDM resources should introduce information early after amputation with the opportunity for revisiting throughout the decision-making process. For example, a referral source or rehabilitation team could introduce a SDM resource at the time of amputation surgery or early in the recovery process, before seeing a prosthetist. In addition, SDM resources on a virtual platform could enable a new prosthesis user to access such resources early when amputation is first discussed, and allow them to reassess their communication and information needs over time. SDM resources should incorporate a method for identifying individual communication needs, supported by various formats of information dissemination (e.g. in-person discussion, written format, etc).[36,41]

Central to both SDM models is the goal of achieving health care decisions that reflect a patient's values and goals.[22,23] Patient values often vary and are shaped by social, cultural, and personal factors beyond the prosthetist-prosthesis user interaction.[42] In addition, the presence of multiple comorbidities and complex health conditions (as is the case with many who experience LLA) often contribute to challenges in prioritizing values and clinical goal-setting.[14,43] In prosthetic care, a new prosthesis user's values and goals are essential for optimizing the design of a prosthesis.[44] However, this work demonstrates a gap in focused goal setting and unclear values for a new prosthesis user, specific to the design of a prosthesis.

Particularly for a new prosthesis user who lacks experience using a prosthesis, it may be difficult to conceptualize personal values and goals related to prosthesis design. Both prosthetists and new prosthesis users in this study acknowledged the importance of early preparation and thoughtful consideration of personal values and goals when participating in prosthesis design decisions. Thus, SDM should provide guidance in values clarification related to prosthesis design to empower focused, active, and meaningful participation in SDM. Value clarification methods may include peer narratives, or a process of rating personal values associated with a risk or benefit of a given decision (e.g. rating a concept on a scale of 0 [not important] to 5 [most important]).[45,46]

Within both models of SDM, patients should be encouraged to explore their personal preferences associated with options for a given health choice to make a decision that reflects their values.[23] Especially in cases of complex information, assistance with constructing preferences may be equally as important as asking about them.[47] The results from this work identify a new prosthesis user's experience as the optimal pathway for constructing informed preferences for prosthesis design options. Experience with a given prosthesis design option introduces a mechanism for exploring perceptions of comfort, function, appearance, and other personal factors that may contribute to a new prosthesis user's informed preference.

SDM is facilitated by a patient's understanding of the role and importance of their personal preferences in a given health decision, thus underscoring the decisional need for exploring and constructing personal preferences, or deliberation.[48] Through the provision of experience with a given prosthesis option and eliciting preferences, new prosthesis users may gain confidence and understanding of their role in decision-making for prosthesis design. Therefore, the SDM process should include resources for gaining experience to achieve informed preferences for prosthesis design decisions. Resources may include introducing methods such as show and tell, or trial use with prosthetic options at the point of care between the prosthetist and the new prosthesis user, or resources for connecting with peers with amputation to discuss experiences with prosthesis design options. In addition, question prompt lists are a method for supporting active conversation between prosthetists and new prosthesis users that may contribute to constructing preferences.[49]

A commonly reported barrier for SDM is a lack of patient knowledge on the rehabilitation process.[14] In the context of the rehabilitation journey with a prosthesis, prosthesis design decisions are dynamic and liable to change. For example, expected changes in residual limb shape and volume early after initiating use of the first prosthesis often warrant modifications or changes to a prosthetic socket. Changes and modifications to a socket may introduce potential changes to prosthesis design, and new decision points for a new prosthesis user. The results from this work highlight the uncertainty that new prosthesis users experience around decision type and timing, as well as a new prosthesis user’s role in decision-making throughout the prosthetic journey.

In other populations where health decisions are multifaceted and similarly distributed over an extended course of time, the lack of anticipatory guidance is recognized to negatively affect disease burden for patients.[50] Furthermore, SDM is limited when patients lack clarity on decision points in their care and understanding of how to be involved in decisions.[48] When considering SDM for prosthesis design, introducing the prosthetic journey may help to elucidate future decision points for new prosthesis users, and assist with activating participation in prosthesis design decisions throughout life.[36] For example, SDM may incorporate methods such as comprehensive “patient roadmaps”, which display information and future health-related changes, allowing patients to anticipate future decisions and health situations, and guiding patient expectations for the future.[51]

There were several limitations to this qualitative study. Prosthetic needs are highly individualized and despite efforts to recruit prosthetists and prosthesis users with a variety of characteristics, the results of this study may not be fully representative of the decisional needs of all prosthetists and prosthesis users. In addition, only people accessible by phone or internet were included, potentially biasing decisional needs to those in certain socioeconomic groups. Finally, the study sample was limited to prosthetists in private practice settings and new prosthesis users with transtibial or transfemoral amputation. Future research should include perspectives from other practice settings and individuals with other levels of amputation.

Conclusion

Prosthetists and new prosthesis users described decisional needs and ideas for supporting SDM for prosthesis design decisions early after LLA. Future steps within the IPDAS criteria for promoting SDM should involve designing decision support that incorporates methods for identifying individual communication needs, clarifying prosthesis user values, and resources that simulate experience for achieving informed preferences, within the context of the overall course of rehabilitation and recovery following LLA. The identified themes can inform SDM resources for prosthetists and new prosthesis users when making prosthesis design decisions.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was funded by the Orthotic and Prosthetic Education and Research Foundation. Contents are the authors' sole responsibility and do not necessarily represent official OPERF views. This work received support by NIH/NCATS Colorado CTSA Grant Number UL1 TR002535. Contents are the authors' sole responsibility and do not necessarily represent official NIH views.

References

1. Schaffalitzky E, Gallagher P, MacLachlan M, et al. Developing consensus on important factors associated with lower limb prosthetic prescription and use. Disabil Rehabil 2012; 34: 2085–2094. [PubMed: 22494367]
2. Esquenazi A Amputation rehabilitation and prosthetic restoration. From surgery to community reintegration. Disabil Rebabil 2004; 26: 831–836.
3. Donaghy AC, Morgan SJ, Kaufman GE, et al. Team approach to prosthetic prescription decision-making. Curr Phys Med Rehab 2020; 8: 386–395.
4. Schaffalitzky E, NiMhurchadha S, Gallagher P, et al. Identifying the values and preferences of prosthetic users: a case study series using the repertory grid technique. Prosthet Orthot lnt 2009; 33: 157–166.
5. van Twillert S, Geertzen J, Hemminga T, et al. Reconsidering evidence-based practice in prosthetic rehabilitation: a shared enterprise. Prosthet Orthot lnt 2013; 37: 203–211.
6. van der Linde H, Hofstad CJ, Geurts AC, et al. A systematic literature review of the effect of different prosthetic components on human functioning with a lower-limb prosthesis.J Rehabil Res Dev 2004; 41:555–570. [PubMed: 15558384]
7. Klute GK, Kantor C, Darrouzet C, et al. Lower-limb amputee needs assessment using multistakeholder focus-group approach. J Rehabil Res Dev 2009; 46: 293–304. [PubMed: 19675983]
8. Murray CD. Don't you talk to your prosthetist?' Communicational problems in the prescription of artificial limbs. Disabil Rehabil 2013; 35: 513–521. [PubMed: 22897605]
9. Makoul G and dayman ML. An integrative model of shared decision making in medical encounters. Patient Educ Counsel 2006; 60: 301–312.
10. Ting HH, Brito JP and Montori VM. Shared decision making: science and action. Circ Cardiovasc Qual Outcomes 2014; 7: 323–327. [PubMed: 24496298]
11. Elwyn G, Edwards A and Thompson R. Shared Decision-Making in Health Care: Achieving Evidence-Based Patient Choice. 3rd ed. Oxford, United Kingdom; New York, NY: United States of America: Oxford University Press; 2016
12. Hoffmann TC and Del Mar CB. Shared decision making: what do clinicians need to know and why should they bother? Med J Aust 2014; 201: 513–514.
13. van Til JA, Drossaert CH, Punter RA, et al. The potential for shared decision-making and decision aids in rehabilitation medicine. J Rehabil Med 2010; 42: 598–604. [PubMed: 20549167]
14. Rose A, Rosewilliam S and Soundy A. Shared decision making within goal setting in rehabilitation settings: a systematic review. Patient Educ Counsel 2017; 100: 65–75.
15. Dierckx K, Deveugele M, Roosen P, et al. Implementation of shared decision making in physical therapy: observed level of involvement and patient preference. Phys Ther 2013; 93: 1321–1330. [PubMed: 23641024]

16. Moore CL and Kaplan SL. A framework and resources for shared decision making: opportunities for improved physical therapy outcomes. Phys Ther 2018; 98: 1022–1036. [PubMed: 30452721]
17. Quigley M, Dillon MP and Fatone S: Development of shared decision-making resources to help inform difficult healthcare decisions: an example focused on dysvascular partial foot and transtibial amputations. Prosthet Orthot Int 2018; 42: 378–386. [PubMed: 29393805]
18. Elwyn G, O'Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ 2006; 333: 417. [PubMed: 16908462]
19. Coulter A, Stilwell D, Kryworuchko J, et al. A systematic development process for patient decision aids. BMC Med Inf Decis Making 2013; 13(suppl 2): S2.
20. Creswell JW and Plano Clark VL. Designing and Conducting Mixed Methods Research. 3rd ed. Los Angeles: SAGE; 2018.
21. Gailey R Predictive outcome measures versus functional outcome measures in the lower limb amputee. J Prosthet Orthot 2006; 18: 51–60.
22. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. J Gen Intern Med 2012; 27:1361–1367. [PubMed: 22618581]
23. Elwyn G, Durand MA, Song J, et al. A three-talk model for shared decision making: multistage consultation process. BMJ 2017; 359: j4891. [PubMed: 29109079]
24. O'Connor AM, Drake ER, Fiset V, et al. The Ottawa patient decision aids. Effect Clin Pract 1999; 2:163–170.
25. Hsieh HF and Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005; 15:1277–1288. [PubMed: 16204405]
26. Creswell JW and Poth CN. Qualitative Inquiry & Research Design : Choosing Among Five Approaches. 4th ed. Los Angeles: SAGE; 2018
27. Gill P, Stewart K, Treasure E, et al. Methods of data collection in qualitative research: interviews and focus groups. Br Dent J 2008; 204: 291–295. [PubMed: 18356873]
28. Hennink MM, Kaiser BN and Weber MB. What influences saturation? Estimating sample sizes in focus group research. Qual Health Res 2019; 29: 1483–1496. [PubMed: 30628545]
29. Guest G, MacQueen KM and Namey EE. Applied Thematic Analysis. Los Angeles: Sage Publications; 2012.
30. Jones J, Nowels C, Kutner JS, et al. Shared decision making and the use of a patient decision aid in advanced serious illness: provider and patient perspectives. Health Expect 2015; 18: 3236–3247. [PubMed: 25439268]
31. McMahon SA and Winch PJ. Systematic debriefing after qualitative encounters: an essential analysis step in applied qualitative research. BMJ Glob Health 2018; 3: e000837.
32. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant 2018; 52: 1893–1907. [PubMed: 29937585]
33. Stacey D, Legare F, Boland L, et al. Anniversary Ottawa decision support framework: part 3 overview of systematic reviews and updated framework. Med Decis Making 2020; 40: 379–398. [PubMed: 32428429]
34. Assarroudi A, Nabavi FH, Armat MR, et al. Directed qualitative content analysis: the description and elaboration of its underpinning methods and data analysis process. J Res Nurs 2018; 23: 42–55. [PubMed: 34394406]
35. Simoni JM, Beima-Sofie K, Amico KR, et al. debrief reports to expedite the impact of qualitative research: do they accurately capture data from indepth interviews? AIDS Behav 2019; 23: 2185–2189. [PubMed: 30666522]
36. Pedlow H, Cormier A, Provost M, et al. Patient perspectives on information needs for amputation secondary to vascular surgery: what, when, why, and how much? J Vase Nurs 2014; 32: 88–98.
37. O'Connor AM, Bennett CL, Stacey D, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2009; 3: CD001431.
38. Gulbrandsen P, dayman ML, Beach MC, et al. Shared decision-making as an existential journey: aiming for restored autonomous capacity. Patient Educ Counsel2Q16-, 99:1505–1510.

39. Kennedy BM, Rehman M, Johnson WD, et al. Healthcare providers versus patients' understanding of health beliefs and values. Patient Exp J 2017; 4: 29–37. [PubMed: 29308429]
40. Elwyn G, Hutchings H, Edwards A, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. Health Expect 2005; 8: 34–42. [PubMed: 15713169]
41. Flynn KE, Smith MA and Vanness D. A typology of preferences for participation in healthcare decision making. Soc Sci Med 2006; 63: 1158–1169. [PubMed: 16697096]
42. Lee YK, Low WY and Ng CJ. Exploring patient values in medical decision making: a qualitative study. PLoS One 2013; 8: e80051. [PubMed: 24282518]
43. Vermunt N, Elwyn G, Westert G, et al. Goal setting is insufficiently recognised as an essential part of shared decision-making in the complex care of older patients: a framework analysis. BMC Fam Pract 2019; 20: 76. [PubMed: 31170920]
44. Webster JB, Crunkhorn A, Sall J, et al. clinical practice guidelines for the rehabilitation of lower limb amputation: an update from the Department of Veterans Affairs and Department of Defense. Am J Phys Med Rehabil 2019; 98: 820–829. [PubMed: 31419214]
45. Lang E, Bell NR, Dickinson JA, et al. Eliciting patient values and preferences to inform shared decision making in preventive screening. Can Fam Physician 2018; 64: 28–31. [PubMed: 29358246]
46. Fagerlin A, Pignone M, Abhyankar P, et al. Clarifying values: an updated review. BMC Med Inf Decis Making 2013; 13(suppl 2): S8.
47. Epstein RM and Peters E. Beyond information: exploring patients' preferences. JAMA 2009; 302:195–197. [PubMed: 19584351]
48. Joseph-Williams N, Elwyn G and Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Educ Counsel 2014; 94: 291–309.
49. Lukasczik M, Gerlich C, Wolf HD, et al. Beyond oncology: question prompt lists in healthcare-a scoping review protocol. Methods Protoc 2020; 3: 9. [PubMed: 31963298]
50. Jordan SR, Kluger B, Ayele R, et al. Optimizing future planning in Parkinson disease: suggestions for a comprehensive roadmap from patients and care partners. Ann Palliat Med 2020; 9(suppl 1): S63–S74. [PubMed: 32036671]
51. Scherer LD, Madock DD, Allen LA, et al. Patient roadmaps for chronic illness: introducing a new approach for fostering patient-centered care. MDM Policy Pract 2021; 6: 23814683211019947. [PubMed: 34277949]

Table 1.

Existing frameworks for shared decision-making, and a priori codes: Three Talk Model for Shared Decision Making[22,23] and the Ottawa Decision Support Framework.[24].

Framework element/code	Framework element/code definition	Example interview guide questions/probes
The Three Talk Model for Shared Decision Making		
Choice talk	Conveys awareness that a choice exists – initiated by either a patient or a clinician. This may occur before the clinical encounter.	What decisions needed to be made about the design of your first prosthesis?
Option talk	Patients are informed about treatment options in more detail.	How do you discuss pros and cons of prosthesis design options?
Decision talk	Patients are supported to explore ‘what matters most to them’, having become informed.	How are prosthesis design decisions made for a first prosthesis?
Initial preferences	Awareness of options leads to the development of initial preferences, based on existing knowledge. The goal is to arrive at informed preferences.	What did you know about prosthetics?
Informed preferences	Personal preferences based on ‘what matters most to patients’, predicated on an understanding of the most relevant benefits and harms.	What information did you need/want?
Deliberation	A process where patients become aware of choice, understand their options and have the time and support to consider ‘what matters most to them’: may require more than one clinical contact not necessarily face-to-face, and may include the use of decision support and discussions with others.	How did you determine the best options for you with your provider?
The Ottawa Decision Support Framework		
Decision type	Class or characteristic of the choice that needs to be made [e.g. developmental transition or clinical options (screen, test, treat, palliate), number of options, degree of risk/uncertainty, seriousness of outcomes, margin for error (i.e. whether it is irrevocable)].	What decisions needed to be made about the design of your first prosthesis?
Decision timing	Time frame or urgency with which a decision needs to be made.	How were prosthesis design decisions made with your prosthetist?
Decision stage	Stages of decision making: not thinking about options; actively thinking about options; close to making a choice; and taking steps or already implementing the chosen option. Deciding not to change or to do nothing may be a viable option.	How were prosthesis design decisions made with your prosthetist?
Decision learning	Inclination to choose one option over the others.	How did you determine the best options for you with your provider?
Decision conflict/ uncertainty	Uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values. (Specify the focus of conflict, such as personal health, family relationships, career, finances, or other life events).	What uncertainties do you have about prosthesis design decisions?
Knowledge	Understanding of the health problem or situation, options, and outcomes (e.g. benefits, harms).	What information did you need/want?
Expectations	Perceptions of the likelihood or probability of outcomes for each option.	What were your expectations for your prosthesis?
Values	Desirability of, or personal importance attached to outcomes of options.	How do you determine what is important to patients for prosthesis design?

Framework element/code	Framework element/code definition	Example interview guide questions/probes
Support	Structured assistance in thinking about the decision and communicating with others (including needed/missing support).	What would be helpful for communicating with your prosthetist about prosthesis design decisions?
Resources	Available, accessible assets that are required to make and implement the decision (including needed/missing resources).	What is important for considering prosthesis design options?
Personal & clinical needs	Age, gender, education, marital status, ethnicity, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social), socio-economic status, and social capital.	Tell me about your amputation and how you started working with your prosthetist.

Table 2.

Prosthesis user interview guide and prosthetist focus group guide, with example probes.

Prosthetist questions [a]	**Prosthesis user questions** [a]
Example probes[a]	**Example probes**[a]
Please describe your professional experience and your role in the clinic	Tell me about your amputation and how you started working with your prosthetist
Years of experience	Reason for amputation
How are goals determined with new patients for using a prosthesis?	**What were/are your goals for using a prosthesis?**
How do you discuss goals with your patients?	How did you discuss your goals with your prosthetist?
How do goals relate to prosthesis design?	How did your prosthesis design relate to your goals?
What are your expectations for patients?	What were your expectations for your prosthesis?
How do you discuss your expectations with your patients?	How did you discuss your expectations with your prosthetist?
Describe how you involve patients in the prosthesis design[b] process?	**How were prosthesis design[b] decisions made with your prosthetist?**
How are prosthesis design decisions made for a first prosthesis?	What decisions needed to be made about the design of your first prosthesis?
What information do you present?	What did you know about prosthetics?
What information do you need/want?	What information did you need/want?
What prosthesis design options do you present?	What prosthesis design options were presented?
How do you discuss pros and cons of prosthesis design options?	How did you and your prosthetist discuss the pros and cons of those options?
What is important to you for considering prosthesis design[b] options?	**What's important to you when making decisions about your prosthesis?**
How do you discuss this with your patients?	How do you discuss this with your prosthetist?
How do you determine what is important to patients for prosthesis design?	How did you determine the best options for you with your provider?
What uncertainties do you have about prosthesis design[b] decisions?	What uncertainties do/did you have when it comes to your first prosthesis design[b] decisions?
What would be helpful for discussing options with new patients?	
What would be helpful for communicating with your patient about prosthesis design[b] decisions?	**What would be helpful for discussing prosthesis options with your prosthetist?**
	What would be helpful for communicating with your prosthetist about prosthesis design[b] decisions?

[a] Semi structured interviews are designed to inquire about target topics, but allow flexibility in question phrasing and probes.

[b] Within interviews, prosthesis design was defined as the selecting parts that made up an entire prosthesis, including the suspension, interface, socket, and distal components (e.g. feet, knees).

Table 3.

Participant demographics: prosthetists and prosthesis users.

Prosthetists					
Focus group number	**Participant number**	**Sex**	**Years of clinical experience**	**Credentials**	**Region of practice (the United States)**
1	1	F	20	CPO	Northeast
	2	M	36	CP	West
	3	M	7	CPO	Midwest
	4	M	10	CPO	Midwest
	5	F	5	CPO	Southeast
2	6	M	10	BOCP	Southeast
	7	F	22	CP	Midwest
	8	M	8	CPO	Northeast
	9	F	11	CPO	Midwest
	10	M	24	CPO	Southwest
3	11	M	16	CPO	Midwest
	12	M	13	CP	Midwest
	13	M	5	CPO	Northeast
	14	M	27	CPO	Southeast
	15	F	10	CPO	Southwest
	16	M	5	CPO	Midwest
4	17	M	36	CP	Midwest
	18	M	11	CPO	Southeast
	19	M	30	CPO	Northeast
	20	F	8	CPO	Northeast
	21	F	13	CPO	West
	22	M	30	CP	West
5	23	M	5	CPO	West
	24	M	2	CPO	Southeast
	25	M	8	CPO	West
	26	F	2	CPO	Southeast

	27	M	5	CPO	Southeast	
	28	F	12	CPO	West	
	29	M	32	CP, BOCO	West	
	30	M	4	CPO	West	
6	31	M	25	CPO	West	
	32	M	28	CPO	Southeast	
	33	M	32	CPO	Southeast	
	34	M	27	CP	Northeast	
	35	M	20	CPO	Northeast	
	36	M	42	CP	Midwest	
	37	F	20	CPO	West	
	38	M	20	CPO	West	
Prosthesis Users						
Participant number	**Age**	**Sex**	**Level of amputation**	**Etiology of amputation**	**Time since amputation (wk)**	**Time using first prosthesis (wk)**
1	64	M	TF	Vascular/diabetes	28.8	7.6
2	32	M	TF	Injury/trauma	14.4	0[a]
3	28	F	TT	Injury/trauma	17.6	9.6
4	52	M	TT	Vascular/diabetes	65	48.1
5	48	M	TT	Injury/Ttrauma	11.1	1.7
6	61	F	TT	Vascular/diabetes	36.9	29.6
7	47	M	TT	Vascular/diabetes	24.1	15
8	30	F	TT	Infection, no diabetes	28.4	14.1
9	58	F	TT	Vascular/diabetes	23.1	19.4
10	50	F	TT	Injury/trauma	34.1	29.1
11	66	M	TT	Vascular/diabetes	76.2	50
12	53	F	TT	Injury/trauma	51.4	40.1
13	32	M	B TT	Injury/trauma	45.1	34.7
14	65	M	TT	Vascular/diabetes	91.4	79.4
15	68	M	TT	Vascular/diabetes	35.3	0[a]

16	67	M	TF	Infection, no diabetes	14.9	0[a]
17	59	F	TF	Vascular/diabetes	104.7	83

Abbreviations: BOCO, Board of Certification, Orthotist; BOCP, Board of Certification, Prosthetist; CPO, American Board for Certification, Certified Prosthetist/Orthotist; CP, American Board for Certification, Certified Prosthetist; TT, Unilateral Transtibial Amputation, TF, Unilateral Transfemoral Amputation, B TT, Bilateral Transtibial Amputation.

[a] In the process of receiving the first prosthesis (e.g. fabrication and fitting).

Table 4.

Resulting themes and example quotes.

Theme	Codes from the Three Talk Model for Shared Decision-Making and the Ottawa Decision Support Framework	Group	Example quotes
1. Acknowledging complexity in communication	Three talk model Choice talk Option talk Decision talk Ottawa Decision conflict/ uncertainty Knowledge Support Resources Decision type Personal/clinical characteristics	Prosthetists	“Inundating them with too much, sometimes they feel overwhelmed and will shut down.” —prosthetist 1 “I would say, I look at whoever comes in with the patient, certainly the patient’s demeanor.....You get a pretty good sense of what’s gonna happen just in the first 10, 15 minutes talking to the patient.” —prosthetist 5 “I usually [have] a pretty good read on a patient if they’re coming in and they don’t have much to say, relying on your clinical ability to figure out what’s the best prescribed prosthesis is important. ‘Cause oftentimes, you don’t know perhaps they’re coming to your clinic after receiving some horrible news about some other medical problems that they’re having and the whole process is just very overwhelming. And so, they’re withdrawing from the whole situation and kinda relying on you to say, well, you’re the person in charge. You handle this. I can’t deal with all this. I got all this other stuff going on or, you don’t know exactly what’s going on and what happens in the clinic.” –prosthetist 9 “I’d say for, you know, for new users, I really just, again, gauge their interest or level of involvement.” –prosthetist 4
		Prosthesis users	“I was learning about different kinds of check sockets. I was learning about suction – this suction and valve sockets, just a lot of different kinds of sockets and feet and inner liners, and learning how to do socks. So it’s just – it’s a lot.” —prosthesis user 3 “As far as the prosthetic itself and what they were gonna use and do with it, I think I kind of took the backseat and just let them go with what they thought. I mean, to me, arguing against what they were doing would have been like ... I didn’t know enough about it to feel like I knew enough to offer alternative by ways.” —prosthesis user 2 “The most important thing to me that I’ve learned especially is to be more of an advocate for myself. But a lot of people just aren’t like that, you know. They’re just sort of willing to do whatever people say. And I was in the beginning, because they knew what they were talking about and I didn’t. But, um, I definitely do wish I started out being more aggressive about it and doing more research before I had my first appointment. But yeah, just being more of an advocate for myself.” —prosthesis user 10 “To me, ... give me the information. Hand it to me, put it in my hand, whatever. Let me go over it. You know, don’t just expect me to make a decision right there and on the spot when you give me a bunch of information..... just know that I’m going to take a day or two to weigh out those options and look what is and what isn’t the best option for me.” –prosthesis user 7 “I would recommend that every company out there...appointment number one, talk through all of the possibilities. So that people have time to think about them.” –prosthesis user 10
2. Clarifying values	Ottawa Expectations Values Support Resource Personal/clinical characteristics	Prosthetists	“I guess that comes down to your first encounter with the patient and really getting to know what it is that’s most important to them.” –prosthetist 4 “I think whenever a patient starts to talk about their goals, one of the first things they mention to me is the level of independence that they want. The first thing they’ll say is, ‘I wanna walk again.’ and then when I start to ask them to break that down, they’ll say, ‘I don’t want to have so-and-so helping me,’ or ‘I don’t want to have a cane.’” –prosthetist 2 “Based on all the information that they give me, I’m like, trying to formulate a design and a plan in my head as we’re kinda talking.” –prosthetist 5 “If someone comes into the office and they say, ‘I really want a Kinnex foot. I looked up the Kinnex foot. This is the foot that I have to have. I really want this,’ it gives you the chance to say, ‘What is it about the Kinnex foot that you like a lot?’ or ‘What is it about the Kinnex that you think will help you meet your ADLs? [activities of daily living]’ and then you find out it’s the flexibility. They love the

Theme	Codes from the Three Talk Model for Shared Decision-Making and the Ottawa Decision Support Framework	Group	Example quotes
			flexibility of it. [Then] you can steer the conversation into maybe something more appropriate” –prosthetist 3 “For me personally, I don’t care a whole lot about cosmesis and I care mostly about function. That’s kinda what drives me. But the lady I worked with this morning, she couldn’t care less about the function of the prosthesis; it’s just about how it looks underneath her pants. And so it’s important to recognize that, and that is the main thing, that’s a success for her. It is cosmesis, really. But I think it’s important to look at all aspects of that, and again, in the interview process.” —prosthetist 4 “if there’s any kinda way... some sort of questionnaire ...to kinda get them thinking about what’s important to them, what their goals are....ways that we can get them to be thinking about the things that are important to them that are specifically relevant to componentry selection. Not just what all is important to you kinda of thing ‘cause I’m sure there’s a lot of stuff that isn’t [relevant]..... not that that’s not important, but if there’s ways that we can kind of direct them to get thinking about things that are important to them that also have direct applications for ours and their decision-making process on componentry selection, suspension methods, –prosthetist 12
		Prosthesis users	“In the beginning, I had no clue what I was dealing with, and I just let her go. If she asked me a question, I gave her my answer. Like she did, literally, first did [in] the orientation. She asked me a lot of questions about my lifestyle and what I like to do, what my hobbies were. So, I’m thinking she may have formed her ideas [for the prosthesis] from that discussion.” —prosthesis user 1 “One of the biggest things with me is falling, the falling risk... I really don’t want to fall.” –prosthesis user 2 “at the end of the day, I’m lazy. I’m not going to lie about that. So, the easier it is, the less amount of maintenance, the happier I am with it”. –prosthesis user 4 “I do have an 87 year old mother. I didn’t want her to really freak out because she really doesn’t understand what is going on. And that I would like a skin to cover the bottom half of the leg, not just to leave all the hardware and everything showing. And [prosthetist] informed me most insurance companies don’t pass it. If they don’t, I will pay. I don’t care what it costs, but it needs to be done. And, luckily for me, my insurance company did pay for it and [prosthetist] was able to put the skin on it... and for other people going through this experience, they have to know what they want for themselves, how they want to have their leg look and talk it over with their person. And understand everything that’s going to be happening and what they have to go through, to get it to work right, to feel comfortable with it.” –prosthesis user 6 “I guess I just wanted to know more about each prosthesis individually and how it pertained to my goals.” –prosthesis user 3 “In order for them to provide me options, I think it was important for them to know who I am and what I’m looking to do.” –prosthesis user 5
3. Recognizing the role of experience to inform preferences	Three talk model Deliberation Choice talk Initial preference Informed preference Ottawa Decision conflict/ uncertainty Support Resources Decision type Decision learning	Prosthetists	“I use a lot of trials. I have a bunch of knees and feet actually right behind me. I use them clinically. I reach out to the reps from different companies and ask if I can trial someone on a foot or a knee and let them take it for a week or two. And I think that establishes credibility, but also motivation from the patient if they do want something else, they’ll be willing to go talk to their physician about why they need something different. And they’ll be able to give specific examples of what this device did or didn’t do for them.” –prosthetist 9 “In an ideal world, we’d be able to try both and see if it’s pin lock or suction, seeing what fits into the person’s lifestyle, what works best for their residual limb, tissue presentation. But unfortunately, we have to kind of make a plan, get the L codes approved, and we’re not really supposed to change suspension type after that’s approved and authorized.” –prosthetist 38 “So the majority of the patients being diabetic and—and maybe K-2, K-1, at least to start out with, I’ll discuss the pros and cons last with them because its’s sort of, again, lack of frame of reference, and I know they’re gonna be fine with what I’m doing with ‘em.” —prosthetist 5 “I usually have show-and-tell. I usually have some models of older legs we have around or, laying out some cutouts of the shuttle lock, how that works, different liners. I think it’s easier to show someone what it looks like than to try to just describe it or show a picture or

Theme	Codes from the Three Talk Model for Shared Decision-Making and the Ottawa Decision Support Framework	Group	Example quotes
			something like that." —prosthetist 15
		Prosthesis users	"I would want to have maybe some testimonies of people who have had the different styles that have worked out for them." —prosthesis user 5 "I watched videos on YouTube from different people that are dealing with amputation. There was one gentleman in particular that I felt had the most helpful videos out there.....I learned a lot... his stuff is what I watched and it gave me good information... if I had questions about what he's saying, I'd come back and ask [prosthetist] about it, see what they thought..... it just gave me good information, ...what to kind of expect, what options are out there for me...I think it gave me a lot of good information." —prosthesis user 7 "I learned that there are quite a few different kinds. Um, and so, I guess, in a way, it was cool to learn about all the different kinds. But then, it was kind of confusing because it was a lot of information about things that I didn't really know about, and I didn't really know how to determine what was going to be best for me without actually experiencing it." —prosthesis user 3 "I wish you could just try different feet and then give them back and decide, you know, that's probably the biggest struggle is that you can't unfortunately do that because they're so expensive.... I feel like I would have to try them. The pros outweigh the cons type of thing. It's not something that you can just say off the bat without trying it." —prosthesis user 12
4. Understanding the prosthetic journey	Three talk model Option talk Ottawa Decision conflict/ uncertainty Knowledge Expectations Support Decision timing Decision stage	Prosthetists	"Because I think the biggest complaint from most of them has always been... I don't know what comes next or, I don't see what comes after this, or how I can get from A to B." –prosthetist 6 "Insofar as we're putting a preparatory prosthesis on someone to start with, I say, "Look, you're gonna be in this from three to nine to 12 months or so, then you have the opportunity to switch things up, do things differently according to what kind of knowledge base we build, you as a patient, me as a clinician having you as a patient." –prosthetist 2 "I'd say for new users...they kinda wanna be guided through the process. And so with a lot of people, I don't discuss pros and cons necessarily, unless they do wanna dive into it. So, for the first amputee, they don't have a good frame of reference yet." —prosthetist 4 "maybe having the opportunity to have a tool that would help them engage earlier and meaningful conversation about the process." –prosthetist 14
		Prosthesis users	"I guess I would want them to say, 'this is what your part is right now.' [then] in three years, 'this is what you're going to be dealing with.'.... if there's like five main facts when you first get a prosthetic and this is what you have to think about for the first process of it, and then go on to the next. The simplicity is the best, I think. But then also knowing the knowledge of all the different parts, to a certain extent...... Because, you know, maybe later in my life, I'm going to be, I will want to be more of a hiker and not play tennis anymore. You know what I mean? So if they're ever changing?" –prosthesis user 12 "my [prosthetist] emphasized this to me multiple times, all the way through the process was, 'at any point we can do something different. At any point we can do something different. You're not locked in to these decisions. If you get this thing home and for whatever reason, you just absolutely hate it? It's OK. We'll do something different, we'll try something different. You're not— you're not locked into a decision about something that you cannot possibly know is going to work until you try.' and I think that made me feel very confident that it's OK to try something and to then say I don't like or it doesn't work or it doesn't fit right." —prosthesis user 11 "There was, like, a million and one things that I was worried about. Pretty much the whole thing because it was such a fast, fast thing. That was a little concerning. I was like, I feel like this is something that needs to be made, taking time. But my concerns changed when they said that week that's not the final socket. So, I felt a little better. And I understood the process more when they told me that. Like, oh ok. Like we've got to try out different things." –prosthesis user 8 "I'm still learning a lot of stuff with it. But as we change some of the different stuff, when we change the socket, because of shrinkage

Theme	**Codes from the Three Talk Model for Shared Decision-Making and the Ottawa Decision Support Framework**	**Group**	**Example quotes**
			and all that stuff, there was different adjustments [prosthetist] made to the actual ankle and foot — that kinda interested me.” —prosthesis user 7

Table 5.

Resulting themes, decisional needs, and suggested shared decision-making (SDM) implementation strategies.

Resulting theme	**Identified decisional need**	**Example quotation**	**Challenges in current prosthetic care**	**Suggested SDM implementation strategies**
1. Acknowledging complexity in communication	Identify communication needs	"That discussion should be led by the person going through the amputation more so than the prosthetist or anyone else. Because everyone is different and in some ways, like, having that pros and cons list, while in general may be helpful to most people, it can be confusing or discouraging for others." *–prosthesis user 3*	• Abundance of information • Complexity of information • Variety of individual needs/ preferences for communication	• Reflection on preferences for communication methods • Extending information exchange over multiple time points
2. Clarifying values	Identify and prioritize personal values	"I often get an answer of, 'what do you want to be able to do' and they just—.... 'Walk'. And that's the extent of it." *–prosthetist 18*	• Lack of preparation for discussing goals and values • Superficial goals and values	• Peer narratives • Values and goals questionnaire • Review before first appointment with prosthetist
3. Recognizing the role of experience to Inform preferences	Develop Informed preferences	"I don't know if there is a tool that way, to provide patients with that kind of experience without actually having those prostheses. I think that was one goal of having amputee peer support." *–prosthetist 33*	• Lack of exposure to options • Lack of experience with a prosthesis • Lack of experience as a person with amputation	• Question prompt list • Show and tell • Component trials • Peer support
4. Understanding the prosthetic journey	Understand the prosthetic rehabilitation process	"I thought I knew it was just my first one and I didn't quite know the process of the second, the third one [prosthetic socket]. I didn't realize I was going to keep the same foot and the same leg."s *–prosthesis user 12*	• Unclear process of prosthesis design • Prosthesis changes/decision points unknown	• Prosthetic rehabilitation process map