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Understanding decision-making in prosthetic rehabilitation by prosthetists and people with lower limb amputation: a qualitative study

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Abstract

Purpose: Little has been published about the process of decision-making between prosthetists and people with lower limb amputation (LLA). The purpose of this study is to identify decisions and factors influencing decision-making in prosthetic rehabilitation from the perspectives of prosthetists and prosthesis users, to identify barriers and opportunities for shared decision-making (SDM).

Methods: Qualitative semi-structured individual interviews were conducted with 13 prosthetists and 14 prosthesis users from three clinics in three states of the Rocky Mountain and Southwest regions of the United States. Transcripts were analyzed using thematic analysis.

Results: Four main themes were identified: *perceived decision points, importance of relationship, balancing competing priorities*, and *experience*. Contrasts between perceptions of

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prosthetists and prosthesis users were related to prosthesis design decisions, and the purpose of communication (e.g., goals for a prosthesis *vs.* goals informing prosthesis design). Both prosthetists and prosthesis users described balancing priorities that contribute to prosthetic rehabilitation decisions, and the role of experience for informing realistic expectations and preferences necessary for participating in decision-making.

Conclusion: Opportunities for improving SDM between prosthetists and prosthesis users include (1) clarifying key rehabilitation decisions, (2) identifying the purpose of initial communications, (3) support for balancing priorities, and (4) utilizing experience to achieve informed preferences.

Keywords

Decision-making; amputation; prosthetic; rehabilitation; prosthetist; prosthesis user

Introduction

Lower limb amputation (LLA) is a high cost, chronic health condition that is complicated by poor health-related outcomes [1]. People with LLA face poorer physical function (e.g., physical capacity, walking ability) [2–4] and psychosocial health (e.g., quality of life, depression) [5,6] when compared to general population norms. In addition to limb loss, poor outcomes can be compounded by underinformed prosthesis users' expectations for function with a prosthesis; prosthesis users do not know what to expect after amputation, and their expectations for returning to pre-amputation levels of function are often unrealistically high [7–9]. The tendency for prosthesis users to believe that parts of a prosthesis determine their ability to walk rather than their own physical ability is a prevalent concern among prosthetic care providers [9]. Thus, misaligned prosthesis user expectations may potentially link to reported low levels of satisfaction for function with a prosthesis [10,11], and prosthesis abandonment rates as high as 34% [12,13]. In contrast, realistic expectations for a given outcome after a health event are associated with successful rehabilitation, adherence to care plans, and improved functional recovery in other populations [14–17]. A method for informing prosthetic rehabilitation expectations in prosthesis users is ultimately needed in order to address poor outcomes after LLA [18].

Managing health around LLA is a complex lifelong process, involving many stages of acute and long-term healthcare (e.g., amputation surgery, post-operative recovery, rehabilitation) [19]. Rehabilitation after LLA may include several health interactions, such as orthopedic, nursing, physical and occupational therapy, pain management, mental and behavioral health, and prosthetic services [19]. One component of rehabilitation after LLA involves the provision of a prosthesis and associated therapy for use, in order to restore function and quality of life [20–23]. As a result, prosthesis users often work with prosthetists throughout their life for prosthetic rehabilitation. Numerous options within prosthetic rehabilitation (e.g., prosthesis design and therapy) are available, ranging in factors such as involved time, expense, maintenance, function, and method of use. Prosthetic rehabilitation options may also depend on health system factors, where care processes may differ depending on location, resources, or insurance coverage [24,25]. Furthermore, decisions within prosthetic rehabilitation are interlaced; prosthesis design decisions often influence prosthetic rehabilitation care plans during prosthetic training and beyond [26]. For example,

microprocessor-controlled prosthetic knee components may introduce safety features and potential for variable cadence, but are often expensive, require specific training and therapy, and provision may depend on available resources. Existing evidence for choosing one prosthesis design option or therapy care plan over another is limited, often leaving multiple reasonable choices that may differ in ways that are meaningful to prosthesis users [22,27]. With respect to microprocessor knees, several different options are available commercially, with limited evidence on differences in function or performance [28]. However, differences in weight, appearance, use, or maintenance of each microprocessor knee option may resonate with an individual prosthesis user's priorities or values. The possible tradeoffs would suggest that prosthesis user preferences should be incorporated into the prosthetic rehabilitation decision-making process [22].

Current clinical methods may assist prosthesis users in identifying and participating in goal setting for rehabilitation, but lack direct connection to prosthetic rehabilitation decision-making [29–32]. Shared Decision-Making (SDM) is one solution whereby clinicians and patients work together to discuss benefits and drawbacks of options for a given health decision, with the goal of achieving a decision that aligns with a patient's values [33]. SDM offers an opportunity for improving patient health outcomes after amputation, by supporting patient autonomy, self-efficacy, and patient-clinician relatedness in health decisions [34]. SDM typically involves evidence-supported patient and clinician communication, and has been shown to improve realistic patient expectations for a given option, reduce healthcare costs, and improve patient satisfaction and adherence to care plans in a variety of other patient populations [33,35–38]. SDM offers a method for improving patient outcomes after LLA through self-determination [34]; in order for a patient to integrate a health behavior (e.g., adherence to a prosthetic therapy plan or a prosthesis design plan), they must synthesize the behavior as it relates to their goals and values [34]. Supporting autonomy by providing choice via SDM allows for the individual to actively transform a health behavior into their own values [34]. In prosthetic rehabilitation, the prosthetist-prosthesis user relationship often extends from early amputation throughout the prosthesis user's life, potentially influencing long-term prosthesis user health outcomes. However, little is known about the prosthetic rehabilitation decision-making process that takes place between prosthetists and prosthesis users.

In order to support SDM between prosthetists and prosthesis users, it is necessary to identify the key decisions and factors influencing decision-making. Qualitative methods are ideal for providing rich detail and a deeper understanding of the values and perceptions associated with a behavior, such as decision-making, within prosthetic rehabilitation. The present study aimed to qualitatively identify key decisions and factors that influence decision-making in prosthetic rehabilitation from the perspectives of prosthetists and prosthesis users. This knowledge is required to assist in the identification of opportunities for SDM in prosthetic rehabilitation.

Materials and methods

Study design

Qualitative thematic analysis informed data collection and analysis procedures, and was used to identify the decisions and factors influencing decision-making between prosthetists and prosthesis users. Qualitative thematic analysis explores key themes in textual data, and is ideally suited for investigating decision-making in prosthetic rehabilitation [39]. This study was approved by the Colorado Multiple Institutional Review Board.

Participants, setting, and recruitment

Prosthetists were purposively recruited to achieve maximum variation in professional perspectives [40]. Prosthetists were recruited from different two prosthetic company partners (three separate clinics) located in Colorado, Arizona, and New Mexico, and selected for recruitment based on variation in the recruitment sample (range in age, gender, and years of experience). Recruitment took place *via* email and phone inquiry. Potential prosthetist participants were enrolled if they actively provided prosthetic care to people with LLA, and excluded if they were unable to participate in an hour-long interview. Prosthesis user participants were also purposively recruited in order to achieve maximum variation in prosthetic rehabilitation experiences. Prosthesis users were purposively recruited from the two of the same clinics (Hanger Clinic), located in Arizona and New Mexico, and selected for recruitment based on variation in the recruitment sample (range in age, gender, level of amputation, time since amputation, and etiology of amputation). Participating prosthetists from the clinic partners were informed of the inclusion and purposive sampling criteria for prosthesis users, and those prosthetists informed potential participants using an approved recruitment flyer. Potential prosthesis user participants were enrolled if they met the inclusion criteria of (1) at least one LLA proximal to the ankle and distal to the hip, (2) older than 18 years of age, and (3) active in prosthetic rehabilitation after LLA (prosthetic care and/or physical therapy). Prosthesis users were excluded if they had an upper extremity amputation only, or if they were unable to participate in an hour-long interview.

Data collection

After obtaining written informed consent, participants provided demographic information via email survey. A female research prosthetist (C.A.) conducted one-on-one semi-structured interviews with all participants over the phone or through online video conferencing. The research prosthetist was not involved in clinical care of any participants, but had prior experience providing prosthetic rehabilitation to people with LLA, and was academically trained in qualitative methods. One prosthetist participant was professionally acquainted with the research interviewer prior to enrollment in the study. No other participants had prior relationships with the research team. A semi-structured interview guide (Table 1) was developed by the study team, using an iterative team-based approach [40]. Some aspects of prosthetic decision making are potentially unconscious or deeply embedded clinical practice [41]; thus, the interview guide questions were designed to generate participant responses focused on the process of prosthetic rehabilitation and decision-making after LLA, including concepts of SDM [42]. Additional probing questions were used to elicit and promote free expression of detailed narratives by each participant.

All interviews were audio recorded and transcribed verbatim. Throughout the semi-structured interviews, field notes were collected to record the interviewer's perceptions of the encounter for reflexivity, and to support qualitative data interpretation. Reflexivity ensures that personal backgrounds and roles that may influence data collection and interpretation are accounted for (e.g., identity, work experiences, history), and helps to reduce the potential for misinterpreting a phenomenon [40]. After each interview, debriefing sessions took place between the interviewer and a second member of the research team (C.A. and M.M.). During debriefing, the interviewer and the second researcher monitored for thematic saturation and discussed content and interview flow, emergent constructs, and areas that would benefit from further probing [43]. Data saturation was defined as the point where no new themes or codes emerged from new data compared to the existing data [44]. After researchers established consensus on data saturation, an additional three participants in each group (prosthetists and prosthesis users) were recruited, in order to ensure saturation and maximize variation in participant sample characteristics. Data triangulation was employed using an audit trail of investigator memos and participant transcripts, to ensure trustworthiness of data.

Data analysis

Transcripts were analyzed using thematic analysis, an approach where theoretical insights were generated from the textual data and used to identify themes [40]. ATLAS.ti 8 qualitative data analysis software was used to organize, code, and analyze individual transcripts. Key steps of thematic analysis include (1) data familiarization, (2) identification of themes, (3) analysis of themes to identify structures, and (4) constructing a theoretical model [39]. A multidisciplinary research team conducted the analysis, including a prosthetist (C.A.), physical therapists (M.M. and D.M.), and a non-dinical professional research assistant (E.H.). First, data familiarization took place through reading and re-reading transcripts [39]. Initial codes were generated systematically by noting prominent concepts in the data, aggregated, and compared to establish a definitive codebook [45]. Codes were established across the first three transcripts in both subsets of participants (three transcripts from prosthetists, three transcripts from prosthesis users), and refined in three rounds of revisions among the initial transcripts. Differences in emerging codes were discussed until consensus was achieved among all research coders. All transcripts were coded by one research coder, and cross checked for consistency by a second research coder to ensure credibility of analysis [45]. Codes were categorized according to commonality, by evaluating final codes both within and across participant groups (prosthetists and prosthesis users). Similarities and differences in participant group accounts were compared. Categories were then analyzed independently by two researchers to develop themes and subthemes [39]. Themes and subthemes were then discussed together, reanalyzed, and refined to establish consensus among the research team using an iterative process during four separate meetings [39]. A final report was produced, and member checking was completed by reviewing resulting themes with associated prosthetist and prosthesis user group participants to ensure validation and trustworthiness of results [40].

Results

A total of 19 prosthetists and 17 prosthesis users were contacted. One prosthetist declined participation, while seven prosthetists and three prosthesis users were unable to be contacted within three attempts. Semi structured interviews (mean ± SD: prosthetists 70.0 ± 9.4 min, prosthesis users 68.6 ± 12.4 min) took place with 13 prosthetists and 14 prosthesis users (Tables 2 and 3). Data saturation was achieved with 10 prosthetists and 11 prosthesis users, and three additional interviews took place within each group in order to ensure saturation [44]. Four main themes were identified as factors influencing decision-making between prosthetists and prosthesis users: *perceived decision points, importance of relationship, balancing competing priorities*, and *experience*.

Theme 1: perceived decision points

Prosthetists and prosthesis users described decisions related to goals for using a prosthesis, the prosthetic rehabilitation process, and prosthesis design. Both groups acknowledged a collaborative approach to decisions on goals and the prosthetic rehabilitation process. However, prosthetists prioritized decisions that notably differed from prosthesis users, specifically around prosthesis design. For example, prosthetists would often emphasize prosthetic foot, knee, or socket design decisions, while prosthesis users would focus on decisions around personal goals. Both groups recognized barriers around collaborative prosthesis design decisions.

Prosthetic rehabilitation process decisions were generally made by prosthesis users and in line with their goals for using a prosthesis. Prosthetists described supporting prosthesis users in decision-making for goals, typically through an initial interview:

> “The biggest way that patients are involved in the decision is in the activity and the goal.”
>
> –Prosthetist 10

Prosthetists would then use the prosthesis user’s goals in order to inform prosthesis design decisions:

> “The patient voices the activity they want to do… so it’s taking into account their goal and then me considering what the prosthetic options are, and then me deciding what would be the most appropriate for that goal…”
>
> –Prosthetist 11

Prosthesis users also described making collaborative decisions with their prosthetist about their goals and their prosthetic rehabilitation process, such as timing of rehabilitation goals, whether and when to engage in physical therapy, or the use of various assistive devices:

> “[my prosthetist] always asked me what it is that I wanted, and so did my therapist at the outpatient rehab. And then they would work towards those goals.”
>
> –Prosthesis user 2

All prosthetists described their key decisions to be associated with prosthesis design, including the prosthetic socket, interface, suspension, and components (e.g., prosthetic feet, knees, torsion units):

> "I just have to decide, what is the best prosthetic interface, prosthetic suspension, and prosthetic foot…. the prosthesis that they need to help them reach that functional goal."
>
> -Prosthetist 2

In contrast, most prosthesis users did not recognize their own involvement in prosthesis design decisions, particularly for a first prosthesis:

> "I didn't make any decision about [my prosthesis]. I don't believe I did… it's just like a basic model. It's just a beginner leg. Just so that I could get on my feet."
>
> -Prosthesis user 3

When prosthesis users were probed about their decisions associated with their prosthesis design, they would often describe decisions around approving or disapproving prosthesis socket fit and comfort of prosthetic alignment, or choosing the cosmetic appearance, or aspects where they were explicitly invited to share their opinion. Prosthesis users were often unaware of the decisions that went into prosthesis design (e.g., prosthetic socket, interface, suspension, components), and acknowledged how their prosthetists would lead prosthesis design decisions:

> "I think the one that I got is the one that pretty much—[my prosthetist] didn't really give me options. I think that's how it was, [my prosthetist] recommended one that [my prosthetist] thought I would adjust to the best, I guess."
>
> -Prosthesis user 5

Overall, prosthetists and prosthesis users prioritized different decision points, which may in part be related to the decisions that prosthetists presented to prosthesis users. Prosthetists described various levels of engaging prosthesis users in decisions about prosthesis design, often interpreting a prosthesis user's motivation, cognition, experience using a prosthesis, or familiarity with the prosthetic process. If someone with LLA did not have prior experience with a prosthesis, or if prosthetists interpreted a lack of interest or engagement by that person, prosthetists would default to making decisions about the prosthesis design:

> "Their first prosthesis I normally make the decision for them 'cause people don't know."
>
> -Prosthetist 6

Prosthetists also recognized the lack of exposure and awareness of prosthesis design options as a barrier for discussing potential prosthesis design options with prosthesis users:

> "My best explanation would be that they don't really understand the difference and sometimes people don't want to talk about things that they don't understand because it's not the most obvious to them."
>
> -Prosthetist 11

Finally, prosthesis users expressed a desire to be more engaged in decisions about their prosthesis design, but discussed how a lack of exposure to options limited their participation:

> "If [my prosthetist] would have given me other options or told me about other things, I would have thought about it and made a decision, but that's the only option [my prosthetist] gave me, so I thought that was the only option."
>
> -Prosthesis user 11

> "I feel like I'd have liked to have had more of a decision, you know, maybe more of a discussion other than just, "This is what you get."
>
> -Prosthesis user 3

Theme 2: importance of relationship

Prosthetists and prosthesis users emphasized the importance of their relationship and therapeutic alliance for decision-making throughout all aspects of prosthetic rehabilitation. Elements of their relationship generally developed through an interview process, establishing trust, providing education, unspoken communication, and inclusion of social support. The relationship between prosthetists and prosthesis users was a key factor contributing to prosthetic rehabilitation decisions.

Prosthetists would develop trust through an initial interview, and described how conversation and relationship-building was necessary for putting prosthesis users at ease, and encouraging them to share personal factors that contribute to prosthetic rehabilitation decisions:

> "when they relax and begin to talk, they share things and aspects of their lives, their ADLs [activities of daily living] that they don't even realize that they're sharing, so that helps me take into consideration what different things I might prescribe for them"
>
> -Prosthetist 9

Prosthesis users also recognized the importance of developing a trusting relationship with their prosthetists, in order to achieve confidence in their prosthetist's care. As patients connected with their prosthetists and developed trust, they would learn about the prosthetic rehabilitation process:

> "Every visit that you go, they get to know you, and you get to know them more and more each time, it gets personal to a point. You make yourself comfortable being around the prosthetic guy. There's some that you could be uncomfortable around and you just don't feel right, but [my prosthetist's] a real professional, explains everything that he's doing or why he's doing the measuring, or whatever he's doing, he explains everything."
>
> -Prosthesis user 14

Prosthesis users described an understanding of how their goals were important for prosthesis rehabilitation decisions, but they often discussed relying on their relationship and trust in their prosthetist for prosthesis design decisions. Prosthesis users acknowledged general awareness of prosthesis design decisions as a product of their discussion on goals; however,

their experience lacked connection between how goals related to specific prosthesis design options:

> "[the prosthesis] was their [the prosthetist's] decision because I gave them what I did, how I lived, how I want to live."
>
> -Prosthesis user 4

Prosthetists and prosthesis users described the importance of their relationship as a source of education on the prosthetic rehabilitation process, use and care of a prosthesis, available prosthetic options, and associated pros and cons. Prosthetists would often use a prosthesis user's initial knowledge assessment to determine how and where to focus further education:

> "I want to know what the patient knows about prosthetics, I want to know where they've been, to know where there might be holes in their understanding or education of prosthetics, because sometimes they know exactly what they want, and then I realize that I need to kind of fill in their base of understanding."
>
> -Prosthetist 4

All prosthesis users valued receiving information and guidance from their prosthetist, and recognized education to be key for gaining awareness of prosthetic rehabilitation decisions and potential options. Education was also essential for informing a prosthesis user's expectations, such as function with a prosthesis or prosthetic rehabilitation timelines:

> "They would ask me questions, and then I would give them the answers, and they would let me know if it was going to be possible to do that, or if it's not going to be possible today."
>
> -Prosthesis user 14

Unspoken communication contributed to relationship-building between prosthetists and prosthesis users, and factored into prosthetic rehabilitation decisions. Unspoken communication was described during the interviews as an interpretation of actions, engagement, social cues, appearance, mannerisms, habits, and goal motivation. Prosthetists described using unspoken communication to interpret prosthesis user characteristics as they related to prosthetic rehabilitation decisions; the interpretation would in turn influence how prosthetists communicated with prosthesis users about potential prosthetic rehabilitation options, and presentation of prosthesis design decisions. For example, a prosthetist often would describe how a prosthesis user's appearance would inform their interpretation of the prosthesis user's hygiene. Their interpretation would then influence the prosthesis rehabilitation options prosthetists would present; options requiring good hygiene, such as certain prosthesis liners, would not be presented for a prosthesis user who appeared to have poor hygiene. Unspoken communication would also inform a prosthetist's estimation of a prosthesis user's potential for achieving goals for using a prosthesis, which would ultimately influence prosthesis design decisions. Prosthetists often discussed challenges with interpreting unspoken communication without trust:

> "It's one of those things that, one hundred percent honesty has to be felt on both ends. You kind of have to feel out, again, just through your interview process. I

> don't think there's any good way to quantify patient motivation- It's just one of those things that you kind of feel through your interaction with the patient."
>
> -Prosthetist 13

Finally, both prosthetists and prosthesis users discussed the role of external social support in relationship-building. Prosthesis users described the role of their family/caregivers for supporting their prosthetic rehabilitation decisions, and the importance of peers with LLA for learning about the prosthetic rehabilitation process:

> "I found somebody that had just gotten a leg …. and I went in there and talked to him, because I thought, I don't know what I will be doing. I don't know the first thing about using a leg and what I do about it. So, I went down there and talked to him…"
>
> -Prosthesis user 13

Prosthetists also discussed the importance of leveraging a prosthesis user's external social support for establishing trust; prosthetists described using family, therapists, and external healthcare providers to validate or refute information supplied by prosthesis users:

> "Sometimes [l] look at the family member, and the/ll be like, 'Yeah, what they're telling you is truly not the case, this is what's really going on.'"
>
> -Prosthetist 3

Theme 3: balancing competing priorities

Prosthetists and prosthesis users described priorities that influence prosthesis rehabilitation decisions, and challenges with balancing competing priorities. Priorities often incorporated a range in physiologic factors, function, life participation, personal, and prosthetic factors. Prosthesis users described weighing their personal competing priorities when making prosthetic rehabilitation decisions, while prosthetists discussed the challenges in weighing their personal priorities with the priorities of their patients.

Prosthesis users described their priorities rooted in their personal goals, life participation, prosthetic factors, and resources. For example, one prosthesis user described goals for starting a running routine, to support weight loss and improved health. His goals for increasing activity when using his prosthesis supported his rationale for pursuing different prosthesis design options (e.g., energy storing components). However, he recognized how financial limitations acted as a barrier for pursuing certain prosthesis design options ideal for running. He discussed his struggle in balancing his competing priorities:

> "I think I had unrealistic expectation, like 'cause I told [my prosthetist] that I wanted to start running and all that stuff…. then he explained to me that as far as a running leg, my insurance doesn't cover the running leg…. So a running leg is not medically necessary to Medicaid, so they wouldn't cover that. Just whatever, helps me, you know, be mobile."
>
> -Prosthesis user 6

Prosthetists also described a process of balancing priorities when considering prosthetic rehabilitation decisions. Prosthetists would interpret and weigh the factors around life participation, personal goals, health, preferences, and physical and social environment described by prosthesis users when considering characteristics of prosthesis design options. Prosthesis design decisions were often influenced by underlying financial resources available to patients for potential options. Additionally, prosthetists discussed the challenges in balancing their priorities for prosthesis decisions with priorities of prosthesis users:

> "As a prosthetist we-we're so in tune to function and we think that everyone's number one is gonna be how well the leg functions, and that's not necessarily true. Some people, cosmetics is more important, and it's something that you have to be a little open to, because if that's what's most important to the patient, then that's what they get"
>
> -Prosthetist 6

Theme 4: experience

Experience with LLA prominently influenced decision-making in prosthetic rehabilitation. As prosthesis users gained experience with using a prosthesis, they would gain increased awareness of prosthetic rehabilitation and design options, understanding of the prosthetic rehabilitation process, and more realistic expectations for using a prosthesis. Prosthetists described challenges in making appropriate prosthesis design decisions before prosthesis users demonstrated success with using a first prosthesis. Prosthetists would often utilize a prosthesis user's experience with a first prosthesis to compare and contrast other potential options for new prosthesis design decisions.

Prosthesis users discussed how experience with limb loss and using their prosthesis would contribute to an increased understanding of the capabilities and limitations of their prosthesis design and the role that it plays in achieving their functional goals. Experience with using a prosthesis would assist with a prosthesis user's understanding of how a prosthesis functioned in their environment, and an understanding of pros and cons associated with a given prosthesis design option. The experience with an initial prosthesis often contributed to a prosthesis user's awareness of different available options and how they linked to certain goals; if an option that was used in the first prosthesis caused discomfort or problems, prosthesis users often described how that experience would prompt an introduction of alternate options by their prosthetists. Over time, prosthesis users described a greater inclination to discuss potential prosthesis design options with their prosthetists, because prosthesis users could then compare and contrast new options with their previous prosthesis:

> "We tried many ones, like the first one was the pin-lock, and then I got the abscess, -[my prosthetist] thought that might have contributed to the ulcer, so that's when [my prosthetist] decided to transition me into the one where you just rest your- put the sheath over it and you just kinda rest your limb into it. At the beginning I didn't know I had an option, I didn't even know there were different styles at all. I just thought it was a prosthetic leg."
>
> -Prosthesis user 6

Prosthesis users described feeling more equipped to ask questions, discuss options, and participate in prosthesis design decisions due to the gained experience with using a prosthesis, thus increasing initiative to approach decisions collaboratively between prosthetists and prosthesis users:

> "I'll be able to ask more educated questions because I've lived through It this far. But in the beginning, you don't know anything."
>
> -Prosthesis user 12

Prosthetists and prosthesis users discussed how their experience with using a prosthesis and progress in achieving goals often helped inform expectations. Both groups expressed difficulty in estimating future outcomes early after amputation, but as prosthesis users gained familiarity with using a prosthesis and progressing with their goals, they reported re-evaluating their own expectations for their performance with a prosthesis:

> "It has taken some time to convince me that I really need to work at things that I thought would be just second nature once I learned them.… I don't expect instant success anymore…"
>
> -Prosthesis user 9

In contrast, prosthetists frequently discussed uncertainty in their expectations for what a prosthesis user could accomplish with their prosthesis, which often translated to uncertainty in their prosthesis rehabilitation decisions. For example, prosthetists often described the difficulty in optimizing prosthesis design decisions early after LLA:

> "You know, I ask all these questions in the interview, and I totally picture something in my head for you, but then you start being active and things change."
>
> -Prosthetist 8

Prosthetists and prosthesis users described how their prosthetic rehabilitation plans would change as prosthesis users gained experience using a prosthesis and monitoring progress. Both groups discussed tracking and monitoring a prosthesis user's progress with using a prosthesis and achieving their goals; the progress or lack of progress would then inform future rehabilitation decisions, such as prosthesis design:

> "We set them up with a new foot, and then we watch their improvement like, jump significantly or you watch that improvement maybe slow down over time and go, 'Mmmm, okay, maybe we need to consider something else for the next foot."
>
> -Prosthetist 12

Discussion

The present study identified four main themes on decisions and factors influencing decision-making between prosthetists and prosthesis users: *perceived decision-points, importance of relationship, balancing competing priorities, and experience*. The identified themes offer insight into potential opportunities for SDM between prosthetists and prosthesis users.

Perceived decision-points

After LLA, prosthetists and prosthesis users effectively communicate about decisions on goals for the first prosthesis and the prosthetic rehabilitation process. Prosthesis users primarily described choosing goals that align with their priorities, and rehabilitation process decisions necessary to attain their goals. This result may suggest that prosthesis users prioritize functional goals and rehabilitation process decisions, potentially indicating a need for examining decision-making beyond the prosthetist-prosthesis user relationship. For example, perspectives from other rehabilitation team members (e.g., physical therapists, physicians, family, and caregivers) on decision making in prosthetic rehabilitation may expand understanding of this finding. However, this work also suggests that prosthesis users lack of awareness of the various decisions that go into prosthesis design, specifically for their first prosthesis, potentially limiting SDM between prosthetists and prosthesis users. Instead, prosthesis users described their primary decisions for their first prosthesis to be their functional goals for using the prosthesis, appearance, and the comfort or fit of their prosthesis, rather than about prosthesis design (e.g., socket, interface, suspension, components).

The limited awareness of the multiple decisions involved in prosthesis design contrasts with existing research in SDM, which has examined more discrete decisions with a finite list of options that are often more obvious to patients, such as a decision for or against a particular surgery, medication, or treatment options for a health condition, such as cancer [46–50]. Specific to LLA, SDM has been examined around the discrete decision for level of amputation surgery (e.g., considering partial foot level amputation versus transtibial amputation) [46]. However, results from this work demonstrate that decisions in prosthetic rehabilitation are multifaceted and complex, including goals, rehabilitation processes, and prosthesis design. Regarding prosthesis design, both groups described how initial decisions about the first prosthesis design are typically made by prosthetists, whereas prosthesis users were more likely to recognize decisions that they were explicitly invited to participate in (e.g., perceived comfort in the socket, goals for using the prosthesis, direct questions about desired appearance, or for experienced prosthesis users, considering alternative design options if the initial design is problematic).

Similarly, Sansam et al. found that prosthesis users were not typically involved in choosing prosthetic components [9], and Murray described how prosthesis users often assumed passive roles in decisions about prosthesis design due to a lack of experience or knowledge necessary to participate in decisions [7]. Communicating the existence of a choice is a key first step in clinical models for practicing SDM [42,51]. While prosthesis users described an increased awareness of prosthesis design decisions after gaining experience with using a prosthesis, particularly for a new prosthesis user, the discrepancy in recognized decision points may be perpetuated by a lack of clarity on the existence of decisions about the prosthesis design. It is likely that the active questioning between prosthetists and prosthesis users around goals, appearance, and comfort/fit of the prosthesis conveys clear communication of the existence of such choices, thus creating an invitation for patient participation in decision-making. SDM involves making a patient aware of a choice [51]. These findings demonstrate the importance of prosthesis user awareness of prosthesis design

decisions, and emphasizes experience, communication, questioning, and feedback between prosthetists and prosthesis users in order for new prosthesis users to gain awareness of decisions and participate in SDM. The results from this study suggest that implementing a similar format of discussion may be helpful for clarifying decisions in SDM.

Importance of relationship

Although the relationship between prosthetists and prosthesis users is strongly valued, it was noted that prosthesis users did not articulate awareness of the connection between relationship factors (e.g., discussion of goals, establishing trust, unspoken communication) and prosthesis design options. Instead, prosthesis users often relied on their relationship and trust in their prosthetist's prosthesis design decisions. Murray reported similar findings, where a well-established relationship between prosthetists and prosthesis users with effective communication played a key role in a patient's ability to achieve informed expectations and satisfaction with a prosthesis [7]. The missing connection may present a gap in current care, and possibly limit a prosthesis user's ability to discuss their personal values as they relate to potential prosthesis design options. For example, a prosthetist and a prosthesis user typically discuss functional goals for a prosthesis, such as hiking on uneven terrain, which may cue a prosthetist to consider certain prosthetic foot options. However, alternate foot options may need to be considered if a prosthesis user also values being able to wear multiple types of shoes with the prosthesis. Currently, identification of such values is dependent on the quality of the prosthetist-prosthesis user relationship, and the ability of a prosthesis user to trust a prosthetist and share their values. In addition to a limited awareness of the decisions that go into prosthesis design, prosthesis users may also be unaware of the role and the importance of articulating various personal values during initial communications.

Although prosthetists and prosthesis users described discussing rationale for some prosthetic rehabilitation decisions, the results from this work suggest that prosthesis users may benefit from understanding how communication during their initial relationship-building influences prosthesis design decisions (e.g., the pros and cons for one option as they relate to a particular goal or value, such as hiking or wearing various footwear). Current clinical measures, such as the Goal Attainment Scale [29], the Activity Card Sort Measure [30], the Patient Specific Functional Scale [31], or the Canadian Occupational Performance Measure [32] assist with identifying goals, but lack a direct connection of goals to rehabilitation decision-making. For example, the measures may support identifying and measuring progress of a goal for walking on uneven terrain, but lack connection with how such a goal might relate to decisions around prosthesis design options. Effective SDM incorporates a process of exploring a patient's goals and values as they relate to a given health decision, to identify potential options [51]. Therefore, prosthetic rehabilitation may benefit from efforts to clarify the purpose for initial communication and relationship-building as a factor influencing prosthesis design decisions, which may support SDM between prosthetists and prosthesis users. Additionally, existing clinical tools that facilitate goal setting may benefit from incorporating direct connection to prosthetic rehabilitation decisions.

Balancing competing priorities

Within the decision-making process, both prosthetists and prosthesis users described the challenge of balancing the priorities that influence prosthetic rehabilitation decisions, most often around prosthesis design options. In early communication, prosthetists interpreted a prosthesis user's motivation for using a prosthesis, which would influence discussion on prosthesis design options. Generally, prosthesis users expressed a desire to participate in prosthesis design decisions, but recognized a lack of discussion on prosthesis design options to consider for their first prosthesis. The lack of discussion on prosthesis design options may further challenge the process of prioritizing values, a necessary step in achieving informed preferences for SDM [51]. For example, a prosthesis user could potentially identify personal goals and values for both hiking and wearing various shoes with a prosthesis, which may introduce different prosthetic foot options with potentially conflicting features. While prosthetists may have extensive experience and well-informed preferences for prosthetic foot options, SDM involves a process of supporting a patient in constructing preferences for potential options, in order to arrive at an informed decision [51]. The results from this work suggest that prosthesis users may benefit from support in balancing their priorities for prosthesis design options with the expertise of their prosthetists.

Many prosthetists in the present study also conveyed difficulty in estimating patient outcomes with a prosthesis, which coincides with existing findings by Sansam et al. [9]. Difficulty in estimating patient outcomes may be in part be due to the extensive amount of physiologic factors, function, life participation, personal, and prosthetic factors that contribute to prosthesis design decisions. Many of the factors identified in the present study are echoed as important factors for indicating successful use and provision of a lower limb prosthesis in existing research [20,52]. Although heavily researched, the converging challenge remains on how to engage patients in discussing and balancing the multiple contributing factors when considering prosthesis design options. SDM involves supporting a patient with exploring and weighing personal values associated with a given option, and through "constructive engagement, [and] helping patients learn about and compare alternatives." [53] The findings from this study suggest that both prosthetists and prosthesis users may benefit from SDM in order to prioritize factors contributing to prosthetic rehabilitation, and weighing benefits and risks of options when deliberating options.

Experience

Prosthetists and prosthesis users discussed how the decision-making process changed as prosthesis users gained experience with using a prosthesis. Experience was a key factor for introducing awareness of prosthetic rehabilitation options, understanding of the prosthetic process, achieving more informed expectations for using a prosthesis, and ultimately, participation in prosthesis design decisions. Prosthetists and prosthesis users would increase discussion and introduce more prosthesis design options once a prosthesis user had experience using their first prosthesis, as a reference for comparing other potential options, and once a prosthesis user demonstrated success in achieving their goals. Prosthetists also benefitted from a prosthesis user's experience, which would assist with aligning prosthesis design options with a prosthesis user's demonstrated prosthesis design needs.

Early after LLA, the lack of a prosthesis user's experience with prosthetic options represents a barrier for SDM between prosthetists and prosthesis users, specific to the first prosthesis. The results from this work suggest that experience as a person with LLA and using a prosthesis may be another important factor for achieving informed preferences. Although time and physically using a prosthesis are ideal for providing experience to a new prosthesis user, prosthetists and new prosthesis users could potentially explore methods for providing experience, such as show and tell of different prosthesis design options, or demonstration.

Limitations

The results from this study should be regarded in light of its limitations. Prosthetists and prosthesis users were recruited primarily from two clinic locations, therefore the findings may underrepresent perspectives from prosthetists and prosthesis users in different locations or business structures. Additionally, data is representative of prosthetists and prosthesis users only, limiting perspectives from other individuals who may influence decisionmaking in prosthetic rehabilitation (e.g., physical therapists, physicians, caregivers and family members). Future research would benefit from incorporating an expanded range in rehabilitation care team participants, participant characteristics, medical settings, and prosthetics practice characteristics. Finally, several existing theories on SDM are available in current research, such as the Ottawa Decision Support Framework [54] and the Three Talk Model for Shared Decision Making [51]. The results from this study have illustrated key decisions and factors influencing decision-making between prosthetists and prosthesis users, which are essential for identifying opportunities for SDM. However, future research may benefit from using existing SDM frameworks to analyze the decisional needs of both prosthetists and prosthesis users, for developing decision support resources.

Conclusion

Understanding the current decisions and factors influencing decision-making between prosthetists and prosthesis users is an important step for improving SDM in prosthetic rehabilitation. Potential areas of improvement were identified in this qualitative study, including (1) the need to clarify and explicitly define prosthesis design decision points, (2) define a purpose for initial relationship and communications, (3) support in prioritizing factors contributing to prosthetic rehabilitation decisions, and (4) considering experience to achieve informed preferences. Incorporating a SDM approach to prosthetic rehabilitation decisions demonstrates potential for improving decision quality, patient satisfaction, and adherence to prosthetic treatment plans.

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IMPLICATIONS FOR REHABILITATION

- Many people with lower limb amputation experience poor physical function and psychosocial outcomes, which may be further compounded by under informed prosthesis-user expectations for function with a prosthesis.
- Shared decision-making offers an opportunity for improving realistic prosthesis-user expectations, reducing healthcare costs, and improving prosthesis-user satisfaction and adherence to care plans.
- Opportunities for improving shared decision-making between prosthetists and prosthesis-users include (1) clarifying key rehabilitation decisions, (2) identifying the purpose of initial communications, (3) support for balancing priorities, and (4) utilizing experience to achieve informed preferences.

Table 1.

Semi-structured interview guide and example probes.

Prosthetist questions
1. Tell me about your professional experience and role in the clinic.
2. What is the typical care plan for someone in your clinic following amputation? *Example probes:* • What information do you use to inform a patient's plan of care? • What do you discuss with patients? • What decisions are being made? • How do you determine frequency/timing/duration/content of rehabilitation? • What influences a change in the typical care plan?
3. Goals: How do you monitor progress in prosthetic rehabilitation? *Example probes:* • How are goals established? • What do you need to know in order to measure progress? • How do you measure progress? • How do you interpret the results? • How does this influence prosthetic rehabilitation decisions?
4. Expectations: How do you determine functional prognosis with each patient? *Example probes:* • How do you know what to expert from your patients? • What factors influence your expectations? • How do you discuss expectations around rehabilitation plans with patients? • How do you incorporate expectations into prosthetic rehabilitation decisions?
5. Describe how you involve your patients in decisions about their treatment. *Example probes:* • How are decisions made about prosthetic rehabilitation? • What information do you give to patients about prosthetic rehabilitation options? • How do you decide which options to present? • What do you discuss with patients when considering rehabilitation options? • How do patients participate in decisions? • What do you think is important for patients when considering options? • How do you know if your patient is comfortable in sharing their opinions?
Prosthesis-user questions
1. Tell me about your amputation.
2. Describe your rehabilitation experience after your amputation. *Example probes:* Describe how you started working with your prosthetist. What kinds of decisions were you making? What information did you want/need during that time?
3. Goals: What were your goals during your prosthetic rehabilitation after amputation? *Example probes:* How were your goals determined? What informed your goals? How did you know what was realistic for you? How does your goals influence your prosthetic rehabilitation? How do you measure your progress in prosthetic rehabilitation? How does your progress affect your prosthetic rehabilitation decisions?
4. Expectations: What was most important for figuring out what to expect after amputation? *Example probes:* What were your expectations after amputation? How did you establish those expectations? How did you discuss those expectations with your prosthetist? How did your expectations influence your prosthetic rehabilitation?
5. Describe how you and your health team made treatment decisions during rehabilitation. *Example probes:* What were your decisions? What options were presented to you? How did you discuss options with your prosthetist? How were decisions made? What was most important to you when making decisions about those options? What things did you discuss with your prosthetist when trying to figure out the best option for you?

Table 2.

Prosthesis-user demographics.

	Age	Sex	Level of amputation	Etiology of amputation	Time since amputation (in weeks)	Race	Additional persons in household	Education
Prosthesis-user 1	36	M	TTA	Trauma	37	White/Caucasian	+3	>HS
Prosthesis-user 2	68	M	TTA	Infection, no DM	97	White/Caucasian	+2	D
Prosthesis-user 3	61	F	B TTA	Infection, no DM	32	White/Caucasian	+1	D
Prosthesis-user 4	53	F	TFA	Blood Clot	38	American Indian/Native Alaskan	+6	D
Prosthesis-user 5	40	M	TTA	DM/VD	300	American Indian/Native Alaskan	+2	>HS
Prosthesis-user 6	45	M	TTA	DM/VD	101	Other, Hispanic	+2	D
Prosthesis-user 7	49	M	TTA	Infection, no DM	66	Other, Hispanic	+3	>HS
Prosthesis-user 8	45	M	TTA	Infection, no DM	76	American Indian/Native Alaskan	+1	D
Prosthesis-user 9	86	M	TTA	Cancer/tumor	7	White/Caucasian	+1	D
Prosthesis-user 10	42	M	TFA	Trauma	87	White/Caucasian	0	D
Prosthesis-user 11	53	F	B TTA	DM/VD	18	American Indian/Native Alaskan	+2	<HS
Prosthesis-user 12	78	M	B TTA	DM/VD	38	White/Caucasian	+2	D
Prosthesis-user 13	69	F	TTA	DM/VD	56	White/Caucasian	0	>HS
Prosthesis-user 14	49	F	TFA	Infection, no DM	71	Other, Hispanic	+5	>HS

TTA: transtibial amputation; TFA: transfemoral amputation; B TTA: bilateral transtibial amputation; DM: diabetes mellitus; VD: vascular disease; H: Hispanic; NH: non-Hispanic; <HS: some high school or less; >HS: high school graduate or GED and/or some college; D: Associates/Bachelors/Masters/professional/doctorate degree.

Table 3.

Prosthetist demographics.

	Years of experience	Sex	Race
Prosthetist 1	30	M	White/Caucasian
Prosthetist 2	28	M	White/Caucasian
Prosthetist 3	9	F	White/Caucasian
Prosthetist 4	15	F	White/Caucasian
Prosthetist 5	6	F	Asian
Prosthetist 6	15	M	White/Caucasian
Prosthetist 7	13	M	Black/African American
Prosthetist 8	2	F	Other, Hispanic
Prosthetist 9	20	M	Black/African American
Prosthetist 10	4	F	White/Caucasian
Prosthetist 11	1	F	White/Caucasian
Prosthetist 12	5	M	White/Caucasian
Prosthetist 13	1	M	Asian