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Perceived External Factors Leading to the Resumption of Occupations

Following Acquired Amputation

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### Abstract

The aim of this study was to determine external factors leading to resumption of occupations after acquired amputation. In this paper, occupation is defined as the role and activity a person deems necessary for daily living. The working hypothesis is that there are external factors that enable prosthesis wearers to resume relevant occupations. Methods: The design of this study included a qualitative (phenomenological) approach. Following HSIRB approval, a convenience sample of two participants was enrolled in the study. The subjects were active clients of a prosthetic training program and met the inclusionary criteria of an acquired amputation and regular use of a prosthetic. Interviews were digitally recorded and transcribed. Analysis was accomplished by independent review of two researchers, followed by simultaneous sharing of themes identified to refine data analysis into working themes. Results indicated emergence of internal factors that, while not the focus of the study, yielded helpful data. External factors that emerged including: Learn to Fall, Finding Occupational Balance, Empathy Motivates, Developing a Support Group, 'Disabled' Stigma, Blessing in Disguise, and Saw it Coming. Conclusion: External factors leading to success can be determined from the perceptions of the prosthetic user which can lead to person centered goal development.

*Keywords:* Occupation, qualitative, success, amputation, prosthesis

## Perceived External Factors Leading to the Resumption of Occupations

### Following Acquired Amputation

This present study utilized a phenomenological approach to determine prosthetic user's opinions on the factors that lead to success after acquired amputation. With a focus on occupations, which is emphasized in occupational therapy we defined occupations as the roles and activities a person deems necessary for daily living and what they deem important to complete. Occupation success post amputation has little exploration among current literature. Searches on success resulted in similar outcomes between studies. Murray's study (2004) took the prosthesis user's opinion on the embodiment of the prosthesis. Some themes discovered include: Adjusting to a prosthetic; The Balance of the Body; Awareness of the Prosthesis; The Knowing Body; The Phantom Becomes the Prosthesis: Extending the Body; and The Prosthesis as Tool or Corporeal Structure. Murray (2009) looked to discover how prosthesis users feel about their prostheses, finding phenomenological themes including enabling prostheses, meanings of cosmesis, and disguising prosthesis use. While Murray explores the meanings of the prosthesis and its use, Schaffalitzky, Gallagher, Maclachlan, & Ryall (2011) took opinions of the prosthesis user and the practitioners to identify the outcomes of prosthetic prescription that are sensitive to user's goals. Schaffalitzky's team also uniquely considered the opinions of practitioners and users creating a different viewpoint on prosthetic prescription. While interesting, they did not determine a focus on success with the prosthesis. These studies represent the currently known qualitative research, and resumption of occupations was not found. The majority of literature on successful prosthesis use is quantitative in nature. Munin et al. (2001) found that among all of the factors examined, the absence of residual limb contracture, visiting nurse upon discharge, and younger ages of subjects showed a relationship to successful

prosthetic outcome. While these findings are significant, along with the remaining quantitative research on success with a prosthesis, none of these studies include a participant-centered approach, which is important in acquiring a better understanding of the factors leading to successful resumption of occupations. The purpose of this study is to begin to fill this research gap and to determine a beginning understanding of how persons with amputations regain occupations after amputation by focusing on their own perceptions regarding the factors leading to successful occupational performance.

## **Methods**

### **Subject Recruitment**

Following approval by the Human Subjects Review Board at Western Michigan University the study was initiated. Participants were recruited at their current place of prosthetic training: The Hanger Clinic, in Kalamazoo, Michigan. To participate in this study the participant must have had an acquired amputation, whether through disease processes or trauma, or any other means other than congenital. The individual must have used a prosthesis to aid them in their daily life or other activities. Two participants were chosen for the study based on these criteria. Both were male, ages 47 and 31, with below the knee amputations caused by disease processes. Participants were approached personally by the investigator wherein an overview of the study was provided including the purpose, objectives, and activities required for participation. If the affirmative response was given, the consent form was presented.

### **Data Collection and Analysis**

Participants agreed to and completed a digitally recorded interview which included demographic profile information followed by a series of questions and probes to elicit best responses to questions related to perceptions of external factors leading to successful resumption

of occupations. Interviews were conducted face-to-face, following an interview script. After transcription, independent thematic analysis of the interviews was completed by the investigators leading to the identification of emerging themes.

**Interview Questions.** The following questions and prompts were devised to obtain those external factors the participants identify as leading to successfully resuming occupations.

- Describe the amount of effort required of you to use your prosthesis. How has this changed over time?
- What do you see as your main occupation at this time? By occupation, I am referring to those major roles that you have now in your life that are most important to you.
- Has this changed since you acquired your amputation? Before amputation, what activities were most important? How did your ability to complete these activities change, if at all, after amputation?
- What activities are now most important for you to be able to complete? If the same, why?
- Identify any other issues or challenges, if any, you faced after amputation and why they were more difficult to complete. How did you overcome these issues or challenges? How did you manipulate your daily activities to make them easier to complete?
- How often would you say that your challenges are experienced by others? Why?
- In what areas of your life do you feel you are successful? What factors do you believe have led you to this success? What areas do you feel are still a work in progress?

- What goals, if any, did you set for yourself when you were first fitted for your prosthesis? Did you accomplish these goals? If not, why? If yes, what helped you achieve them?
- What are your future aspirations and goals? Do you feel that these will be limited by your prosthesis? Or did you change your future goals due to having a prosthesis?

### **Results**

Eight themes emerged from the analysis of the interviews which portrayed the prosthetic user's opinion on the external factors that enabled them to be successful in resuming their occupations. The themes identified were Learn to Fall, Finding Occupational Balance, Empathy Motivates, Developing a Support Group, 'Disabled' Stigma, Blessing in Disguise, and Saw it Coming.

#### **Internal Factors**

While internal factors were not the focus of this study, three internal factors emerged from the data and were worth mentioning. These were Perception, Premorbid Innovation, and Therapeutic Humor. Perception came from the mindsets and positive outlooks held after amputation that aided in being successful in their every day lives. Being creative before amputation and utilizing that creativity after to solve new challenges that had arisen due to the amputation we called Premorbid Innovation. Therapeutic Humor emerged through stories the participants told of using humor and lightheartedness to overcome challenges and emotionally tough situations

#### **Learn to Fall**

The overarching concept that covers this factor is the participants experienced that sometimes they may have to fail at a challenge first before being successful.

Interview 2: “If you fall, you fall. You’re going to get hurt, but you aren’t going to get hurt that bad. I’ve fallen.”

These first failures came in three different forms for the prosthetic user, namely Small Things Matter, Prosthetic Challenges, and Limitations. All of these follow the general concept of failing first to succeed.

**Small Things Matter.** Both participants discussed dealing with small issues they experienced every day.

Interview 2: “Well you can’t sleep in it. That stinks. Getting up to go to the bathroom at night... and taking a shower can be a pain. But it’s not *that* bad.”

Interview 1: “It’s just the pain of putting it on. I don’t mean ‘pain’ pain, but it sucks putting it on every morning.”

These small daily challenges may seem insignificant, but to the prosthetic user can be great accomplishments. This is evidenced by each participant mentioning similar cases as outlined above. As both of the participants later report how these specific situations and other small everyday issues becoming easier with time, it can be said that these challenges used to be more difficult, therefore, making their ability to overcome these challenges more important to them to complete.

Interview 2: “Just day to day stuff, you know, take care of the kids, drive, being able to move fast if you have to right after one. I mean, just being able to do the smallest things... Anything that a person with two normal legs takes for granted every day.”

In response to a question asking what the most important activities to complete are for the participant now, this answer was given. This reiterates the importance of accomplishing the everyday, small tasks the participants face. Furthermore, these accomplishments can act as



motivation to continue to complete the everyday tasks, as well as for those more difficult areas that may require more effort and determination.

**Prosthetic Challenges.** Utilizing a prosthetic limb results in a different set of challenges the user must overcome. Becoming more familiar with the prosthesis and how to use it safely and effectively was identified by a participant.

Interview 2: “Balance is the hardest thing. I said that a 1000 times, I know, but it’s the hardest thing to overcome. The bending over to grab something, especially a heavy object.”

The same participant stated another issue dealing with his prosthesis.

Interview 2: “You used to be able to take a step over and adjust yourself, and now you’re flatfooted, and not putting too much weight on your other leg, and not hurting your other ankle. These are the biggest things.”

Adjusting to the new aspects of the prosthesis is one of the first challenges the prosthetic user may face. However, it is one of the first they overcome as well. The same participant later states that while balance is an issue of which he is still continuing to adjust to, he has been successful to some degree. One study supports balance as an important issue dealt with by prosthetic users and practitioners. “Balance and safety were seen as key physical outcomes of using a prosthesis by both users and practitioners. It was important for service providers that a sense of balance was achieved so that the user was able to walk safely” (Schaffalitzky et al., 2011, p. 1318). This importance testifies to the need to accomplish this challenge, and to how balance is significant to the prosthetic users.

**Limitations.** Learning limitations is another way the prosthetic users Learn to Fall by first failing before becoming successful. Every challenge is faced through the use of trial and

error, until the limit is discovered. The prosthetic user must first overcome the limitation of themselves, however, if they are to succeed at all.

Interview 2: “You just gotta put your mind to it and do it, you can’t just sit back and feel sorry about yourself. That’s the biggest limitation that anybody [has] is if they tell themselves that they can [or] can’t do it. Next thing you know, your only limitation is yourself... If you don’t do it, you don’t do it.”

Limiting themselves leads to restrictions on the degree of success they are able to accomplish. By discovering these boundaries, the prosthetic user can narrow the focus of effort into that area in order to develop the skills necessary to overcome it. The participant also notes that it is important to be aware of the restrictions that cannot change, accept them, and create goals based on these.

Interview 2: “Even if I had some limitations in there, I would’ve been okay with it. I am okay with it. But I just want to be able to do at least 80-90% of the same stuff I used to. If I can’t do a few things, I can’t do a few things.”

Limitations set by the self create boundaries in all aspects of the prosthetic user’s life. Once these are discovered, progress can be made to overcome the limitations to create success in these areas.

### **Finding Occupational Balance**

Disruptions in roles the prosthetic user had before amputation is to be expected. This external factor developed from the themes of regaining balance in the occupations they once had, and the outcomes of those disruptions. Both participants identified with their work roles the most before amputation, but are now more focused on their family roles.

Interview 2: “I’m an at home dad... I’m going to try to go back to work this summer part time; I’ve already got a job set up... Soon I’ll be driving truck and delivering flowers and stuff. And that will be fun... I’m ready to go back to work, and do it all again.”

Interview 1: “I was never home before, I always worked 70 hours to 80 hours a week.”

In response to the question asking where the participant believed they were most successful in life, his response was:

Interview 1: “I could probably say my family life. It got a lot better...”

The success was finding the balance with their new roles in reference to and with their old roles. While both participants state that they are still in process of finding work or returning to work, they have established balance in their lives through taking on the commitment to their family role. Another area of life they established balance in was leisure activities. Both participants reference an increase in leisure activities, when able.

Interview 1: “I’m a hell of a cook now.”

Interview 2: “I ran last night for the first time on this leg and it was hard, it was different than my last [prosthesis], but I did it. I mean, I did it without falling.”

The accounts given of these participants lives portray the depth of occupational balance and the challenge it creates, but also its resulting success.

### **Empathy Motivates**

The encounters that amputees face can only be truly understood by those who have also undergone amputation. This empathy can only be given to others, and success was stated to be a result of the empathetic interaction.

Interview 1: “I went to visit some older people that had lost [a] limb, and again, they were *stuck in their chairs*... and I just talked to them, and two of them had the courage to get up and try to do walking with a prosthetic after. They told me their biggest fear, wasn’t a fear, but more of a hatred. They didn’t want people working with them that were nothing wrong with them and didn’t know what they felt like, or what they were dealing with.”

Having someone talk to the other amputees who have been where they are and experienced similar challenges removed animosity resulting in attempts to no longer be “stuck in their chairs.” The first efforts at successful resumption of occupations occurred in these amputees due to this participant’s empathy.

### **Developing a Support Group**

A support group is defined here by one that is created, not preformed and maintained through attendance to meetings. One participant discussed this factor in how he developed his group in those important to him around him, and who were interested in his success.

Interview 2: “My fiancé has really helped me out a lot... if I had questions, I could always call [Hanger] right away and someone would talk to me. That was always a good thing, like being able to know you can count on your doctors, health care people, [and] the prosthetic people...”

The same participant discussed another amputee who had a different experience, in which those around him allowed him to remain complacent in his occupations.

Interview 2: “I knew one guy I met after I got my leg cut off. He’s 50, but he seems to think everything limits him... I can just see it’s his attitude and the way his wife ‘Okays’ [his behavior].”

This participant points out the necessity of having a group of people around an amputee to push and aid in order to avoid becoming complacent with the level of success, or lack thereof, already accomplished. This group of people becomes someone the amputee can trust and rely on for help in situations faced, which may allow the amputee to overcome challenges that previously may not have been possible.

### **‘Disabled’ Stigma**

The word “disability” carries a connotation that one is inferior or inadequate when completing tasks due to a disadvantage and therefore is in need of assistance. This factor emerged from the underlying themes of others treating the participants as if they were disabled, and the participants’ attempts at removing that stigma from themselves.

**Employer Rejection.** One participant discussed his desire to return to work, but being unable to do so, due to being an amputee.

Interview 1: “The ability is still there, just can’t find the work. So I know I can still do whatever there is to do, just nobody wants to take a chance on hiring somebody that is my age and my, what they consider, disability.”

Interestingly, this participant is clear at distinguishing that potential employers are the ones who declare his missing limb a disability. It could be assumed then, that the participant does not consider himself to be disabled, but rather very capable and withheld the opportunity to prove himself otherwise. This rejection could be resolved if an opportunity were to be given to the participant to successfully demonstrate his abilities, thereby removing the stigma placed on him by others.

**Being like Everybody Else.** Returning to normalcy was identified through goals the participants stated they wished to complete. These goals, by aiding them in being more

‘normal,’ would in turn remove the disabled stigma and resulting judgment received when they were identified as an amputee. One participant established a goal that he was determined to complete:

Interview 1: “I didn’t care what it took I wasn’t going to walk with a limp, and I was going to be able to walk stairs... People don’t know when I walk stairs, if I have pants on, that I have a prosthetic.”

Interestingly, this participant thought it was important to mention that others would perceive him to not be wearing a prosthetic device because of how well he accomplished this goal. It was significant to the participant that other people would not identify him as an amputee by his gait. Murray (2009) stated something to the similar, that “participants referred to a poor walking gait, for instance, as revealing to others and able to draw ‘stares’” (p. 578).

Returning to normalcy in everyday activities was identified by the other participant.

Interview 2: “Working full time, and go back to living what people consider normal. Just doing everything everybody else does. Go back to work... doing everything everybody else does without having disability or not worrying about that stuff anymore.”

This participant specifically mentioned ‘without disability.’ Both participants do not see themselves as disabled, and desire to not be labeled as such. Therefore, they put great effort into their goals to not be labeled by others as disabled, and this is what pushed them to their successes.

Another side of ‘Disabled’ Stigma is being treated differently after amputation. One participant stated:

Interview 1: “It’s always the elephant in the room when someone sees it.”

He continued by revealing the frequency of this happening and the awkwardness that follows until he addresses the amputation himself. Furthermore, this participant spoke of other people expecting him to be disabled.

Interview 1: “Just a lot of people treated me different right off the bat, they wanted me to be more, useless, than I actually was, it seemed like. Lots of people wanted me to just sit back and be catered to because of the things my whole family has been through, dealing with diabetes. And then when I did stuff that wasn’t conforming to what they expected, they were all like *gasp*.”

Other people’s expectations of this participant were that he should be unable to activities because of his amputation. They placed the ‘Disabled’ Stigma onto him anticipating him to fit into their expectations instead of overcoming them. These other people were then shocked to have the participant become so successful after his amputation. Overall, removing the stigma from themselves has pushed these participants to success in their occupations.

### **Blessing in Disguise**

This factor emerged from data that suggested the presence of unexpected benefits resultant of the participant’s amputation. In terms of this participant’s occupations, he stated that he had more issues with his family role before amputation because of his focus on his work role.

Interview 1: “I didn’t have any issues or challenges after the amputation, I had more of an issue before.”

Later he went on to describe this in more detail:

Interview 1: “Like before I knew my kids, [but] I didn’t. I wasn’t a part of my kids’ lives, I was [just] their dad, because I worked all the time. Once that

happened it was cool. I got to see them finish off their high schools and stuff, and before I probably wouldn't have.”

The amputation removed the opportunity to remain in his main role, his work role. This however, allowed for the participant the development of his family role to take place, and to flourish. Without the amputation, he “probably wouldn't have” had the chance to become successful in his family role. Furthermore, this role change and its subsequent success are perceived positively by the participant, noted when he stated:

Interview 1: “Now, I can't say I'm glad it happened, but a lot of cool things have happened since [the amputation occurred].”

The participant's amputation resulted in a positive experience for the participant, and one that resulted in success with his family role rather than just his prosthesis. This success, however, would not have transpired had the amputation not occurred.

### **Saw it Coming**

This factor emerged from the themes of having prior awareness to their own amputation and previous exposure to amputations. To one participant, knowing beforehand that he was going to have his leg amputated gave him a chance to prepare for this life change.

Interview 2: “I knew I had a surgery day coming up, I could prepare. Where most people who have it happen... they don't see it coming. I got to see it coming. It prepares you a little bit better, than someone who loses it right away.”

Clearly, losing a leg abruptly does not allow the amputee the chance to condition himself mentally and physically for the ordeal. Therefore, having prior awareness that the event was



to occur allowed for the participant to be more successful in his occupations, due to the ability to prepare that knowledge provided.

Previous exposure helped the other participant be motivated to not become restricted by a wheelchair for the rest of his life.

Interview 1: “Just because I don’t want to be *stuck*. I’ve dealt with diabetes my whole life, my whole family has it. So I have seen people that have lost limbs and ended up just sitting in their chairs for the rest of their life until they kicked off. So, I didn’t want to be like that.”

This participant had seen first-hand people who had lost limbs and let it limit their lives. Having this previous exposure allowed him to visualize what he did not wish to become, and let that inspire him to be more than what he had seen. Furthermore, it reduced the traumatizing effects losing a limb can cause.

Interview 1: “I’ve had family members that lost limbs, so it gave me a ‘leg up.’ So it was traumatic, but not overwhelming. Maybe because I had some experience with that... [it] could have given me a little bit of an edge.”

Witnessing amputations occur with his family members helped him to be successful with his own experience because it was not overwhelming to him. Previous exposure to other amputations allowed the participant to become more successful in his occupations by creating motivation and reducing the trauma experienced.

## **Conclusion**

Theoretical applications of this study are to fill the research gap currently held in this subject area and to aid those who are to rehabilitate the amputee in understanding what leads to success in occupations. As previously stated, this study is the first, of the researcher’s

finding, that explores the factors that lead to success in the opinion of the prosthetic user. It is important to note then, that external factors that lead to the success in occupations of the prosthetic user can indeed be found by way of qualitative study. Furthermore, filling this gap allows for better understanding of the prosthetic user and to what the professionals aiding in rehabilitation can do to ensure success. This study also allows for a deeper understanding of the prosthetic user's experience. Such experience is often not encountered for those professionals who are assisting the prosthetic user. This then creates an opportunity for greater empathy and comprehension by those professionals.

### **Limitations**

The aim of this study was to reach a beginning understanding of the topic. Therefore, the sample size of two participants was smaller than needed to create a saturation of data. This limited sample size was also recognized to have similar demographics, with sex, age, reason for amputation, and relative location of amputation. Lastly, this study's scope was limited. The participants were recruited from one prosthetic training facility in Kalamazoo, Michigan.

### **Recommendations for Future Study**

Additional research is needed to fully understand and create a saturation of data on this topic. Participants should range in amputation limb locations, sex, age, and reasons leading to acquired amputation. Creating this variety in demographics will produce a greater scope of data, generating the potentiality of a greater understanding of the topic. Further research should assemble participants from other locations to expand the scope of the study, especially moving outside of the region to remove possible biases retained in the area. Lastly, future study should include a focus group with the stakeholders for confirmation and adjustment of themes acquired from the data.

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