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## User experiences of digital prostheses in daily functioning in people with an amputation of thumb or finger

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### ABSTRACT

**Study Design**: Qualitative research design using interpretative phenomenological analysis (IPA) to interpret users' experiences with digital prostheses.

**Background**: Digital prostheses are rarely used, and little is known about the experiences of traumatic finger amputees with digital prostheses. When advising patients regarding digital prostheses, it is crucial for professionals to understand users experiences of wearing a digital prosthesis and the meaning attached to wearing a digital prosthesis.

**Purpose of study**: The aim of this study was to explore and understand users experiences of wearing a digital prostheses in daily functioning.

**Methods**: Individual semi-structured interviews were conducted, recorded, and transcribed. The written interview texts were analysed following Interpretative phenomenological analysis guidelines.

**Results**: Four participants were interviewed. They experienced the prostheses as valuable additions to their daily functioning. Three different themes relating to wearing and using digital prostheses emerged from in-depth analysis of the data: How the prosthesis supporting them regaining a 'grip' on life, reduced overload on unaffected side and restored body image.

**Conclusions**: This study provides a deeper understanding of the experiences of people with digital amputations who use prostheses. Most importantly, that a prosthesis is of crucial importance for participants to be able to act independently and autonomously as well as to participate in family, work and social environments. This insight will help practitioners when considering, with clients the most appropriate digital prosthesis to meet their goals.

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### Introduction

Digital amputation is a condition that is often seen in hand therapy practice. Clinical experience shows that hyperesthesia and loss of strength, grip, dexterity and appearance are the main complaints experienced by patients and shared with the hand therapist. Pillet et al.<sup>1</sup> state that partial or total loss of a finger can have an important effect on aesthetics and functionality for patients. Digital prostheses can fulfil various needs for patients, such as improving grip, strength, and manipulation of objects; restoring

body image; or any combination of different possibilities.<sup>2-7</sup> However clinical experience seems to indicate that few people with partial hand amputations appear to opt for a prosthesis. In addition, an observed lack of prosthetic options, and poor outcomes in the past may be holding back physicians from prescribing a digital prosthesis.<sup>6</sup> As a result, digital prostheses and thumb prostheses are rarely prescribed and/or used.

Digital amputation and partial hand amputations appear in a large range of variations and, therefore each case needs a unique individualized design of prosthesis. On the one hand, the active range of movement of the remaining fingers must be used optimally. On the other hand, the design of the digital prosthesis should help to improve grip patterns, and movements. Above all, it is important to know what tasks and activities are considered important, and problematic in execution by persons with partial hand amputation. In their study, Whelan et al.<sup>5</sup> used the Flinn

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Performance Screening Tool (FPST)<sup>8</sup> to map the valued life activities of 15 participants with partial hand amputations. A personal goal profile was developed for each participant, which included as many as 62 tasks. From all the activities collected, ten activities including cutting meat, peeling vegetables and trimming nails, were identified by 60% or more of the cohort as important and difficult to perform. With this information, the prosthesis with personalized modifications for performing the meaningful activities could be made. Functional goals of the user should be known before the prosthetic fitting, to ensure that the design and function of the prosthesis meet the unique needs of the user. Schultz et al.<sup>9</sup>, found a lack of agreement between users and professionals regarding users' objectives in prosthesis wearing. Upper-limb prosthesis users consider the function of a prosthesis to be the most important factor, followed by comfort and cosmetics, but professionals consider comfort to be the most important factor, followed by function, and cosmetics.<sup>9</sup>

Therefore, it is crucial for professionals to understand and also anticipate for users' experiences in prosthetic use, to improve prosthetic design and functional outcomes.<sup>5</sup> Few scientific studies were found on the use of digital prostheses, with none being found on the user's experiences of wearing a prosthesis. Studies found focused on different aspects of hand function and prosthesis use. Hand function is a composite of hand movement, prehension, sensitivity (pressure, texture, temperature), force, and proprioception.<sup>10,11</sup> The results of the studies provided interesting ideas related to the use of a digital prosthesis. As example, the purpose of a prosthesis may change over time for amputees. Initially, a prosthesis may contribute to the coping process as psychological support.<sup>7,12,13</sup> At a later stage, a prosthesis may no longer be needed.<sup>2,3,13</sup> Factors that influence not wearing or wearing less of a prosthesis include: problems with the stump<sup>12</sup> the unsatisfactory aesthetic appearance of the prosthesis,<sup>2,13</sup> and the digital prosthesis obstructing with hand function. An increase in self-confidence also corresponded with a decreased desire to wear the prosthesis.<sup>2</sup>

The use of a prosthesis results in an improvement of hand function.<sup>14</sup> However, studies examining hand strength have found no evidence that prostheses contributed to hand strength, although some users experienced improved grip.<sup>15,16</sup> This suggests that a digital prosthesis can improve both grip and hand function. However, the studies that were found were from the perspective of the practitioner or prosthetist or considered the functional capabilities of a prosthesis. No studies were found which explored users' experiences of using a digital prosthesis in daily life. This perspective is important because the value of using digital prosthetics can only be identified by the users themselves. To be able to give informed prosthesis advice as a practitioner or to provide the most appropriate prosthesis as a prosthetist, knowledge of user experiences is invaluable. Therefore this qualitative study aimed to explore user experiences of digital prostheses in daily functioning.

## Methods

### Study design

A qualitative descriptive method with a phenomenological approach, using semi-structured interviews was used to investigate the lived experience of using a digital prosthesis. Interpretative phenomenological analysis (IPA)<sup>17</sup> was used as it facilitates in-depth exploration<sup>18</sup> in relation to how individuals experience and ascribe meaning to a specific phenomenon. It can be especially useful when a study is concerned with the complexity, process or novelty of lived experiences.<sup>19</sup>

**Table 1**

Inclusion and exclusion criteria for the sample of digital prosthesis users.

Inclusion	Exclusion
<ul style="list-style-type: none"> <li>◆ Thumb: Amputation between the carpo-metacarpal joint and the interphalangeal joint</li> <li>◆ Finger: Amputation between distal to the proximal third of the proximal phalanx and the distal interphalangeal joint</li> <li>◆ Traumatic</li> <li>◆ Digital prosthesis</li> <li>◆ ≥6 mo after receiving prosthesis</li> <li>◆ ≥18 y old</li> <li>◆ Strong knowledge of Dutch language</li> </ul>	<ul style="list-style-type: none"> <li>◆ Amputation of the thumb proximal to the carpo-metacarpal joint or distal to the interphalangeal joint</li> <li>◆ Amputation of the fingers proximal to the proximal third of the proximal phalanx or distal to the distal interphalangeal joint</li> <li>◆ Arthrodesis of joints in other fingers</li> <li>◆ Thumb and finger amputation</li> <li>◆ Involvement of both hands</li> <li>◆ Unresolved work compensation</li> <li>◆ Significant psychological issues, such as denial, anger, depression, and disempowerment</li> </ul>

Purposive sampling was used on the basis of relevance to the research.<sup>20, 21</sup> To be considered for the study, people had to use a thumb or finger prosthesis and visit the selected rehabilitation center. Potential participants were selected through checking the electronic patient record using the inclusion and exclusion criteria (presented in Table 1). Twenty patients with thumb or finger amputations who had previously been supplied with a prosthesis by the Rehabilitation Department were invited by mail to participate in the study.

### Data collection

Semi-structured one-to-one interviews were used. An interview schedule with a broad focus on the use of a prosthesis in all areas of daily life; experiences with a prosthesis and ways a prosthesis is valued was used (Appendix A).

Face-to-face semi-structured interviews lasting 45-60 minutes were conducted by the first author between November 2017 and January 2018. The interviews took place in a quiet, private room at a Rehabilitation Department. They were digitally-audio recorded and additional notes were taken. The recorded data and transcriptions were stored separately in the institute's secure digital environment. The recordings were destroyed after transcriptions. The data was kept for the research and destroyed afterwards. The participants knew that the researcher was an experienced hand therapist in the field of prosthetics and also a core member of the upper extremity therapy team. One participant had previously been treated by the researcher. To try to reduce bias, prior to the interview the participant was asked to approach the interview as if the interviewer was unknown to them or field of prosthetics. At the end of each interview, the topics discussed were verbally summarized and the participant was asked to indicate whether the summary was accurate and whether anything needed to be added. The recorded oral interviews were transcribed by the first author, and the verbatim transcripts were sent to participants by email for validation before the analysis was conducted.

### Ethics

Ethical approval for the research project was given by the College of Health and Social Care Research Ethics Committee at the University of Derby in the UK, and the local Medical Ethics Review Committee in the Netherlands.

Written, informed consent was gained from each participant prior to the interview. Anonymity was ensured and the information obtained was treated confidentially. Participants names were replaced with pseudonyms.

### Data analysis

The data analysis was conducted in an ideographic, systematic, and interpretative way.<sup>17</sup> The transcripts were analyzed by the first author using IPA 6 steps guidelines for content analysis.<sup>17</sup> Box 1 shows how the IPA was applied in the present study. Each transcript was read several times and the digital-audio recording listened to. Secondly the transcript was analyzed, descriptive comments and linguistics comments were noted, and then interpretative notes at conceptual level were written in question form. From the analysis of the descriptive content and language use, themes emerged in each interview. Each interview case was then examined to determine how these themes related to each other and, themes were grouped into main themes. Final themes, relations between themes and main themes were discussed between the first and second author, although peer review was not performed. The final phase was the search for analogies between the 4 cases by placing the super-ordinated themes of the different cases next to each other to search for similarities. Data saturation was not able to be reached due to the small sample size achievable within the time scale of the study.

**BOX 1.** The application of Interpretative Phenomenological Analysis in present study

*Six steps of analysis according to Smith et al. (2012).*

#### 1 - Reading and re-reading

Careful attention was given to interviews to ensure that the researcher read well and listened to what was said. Transcript of the interview was read several times and simultaneously was listened to the audio recording of the interview. This focus led the researcher's analytical attention to the participants and to make sense of their experiences.

#### 2 - Initial notes

The text was examined for semantic content and language use to become more familiar with the text. Exploratory comments were noted in de right margin of the verbatim. The exploratory comments have been written from different focus. First, the transcript is analyzed to describe content (descriptive comments), then, use of language is analyzed (linguistics comments), and thirdly, interpretative notes at conceptual level were written in question form (conceptual comments).

Subsequently, the text and annotations were read and re-read backwards and forwards, per sentence, and paragraph

#### 3 - Emergent themes

The next phase was the development of emerging themes, following the analysis of the exploratory comments. These emerging themes were noted in the left margin of the verbatim.

#### 4 - Connections across emergent themes

The next phase in the analysis was to type out the emergent themes in a list. After printing, this list of themes was clipped so that each theme was on a separate piece of paper. The themes were moved around to explore spatial representations of how emergent themes related to each other.

#### 5 -Next case

Repeat from steps 1-4 for the remaining cases.

#### 6 -Patterns across cases

The final phase was the search for analogies between the different cases. The super-ordinated themes of the different cases were placed next to each other and searched for similarities.

## Findings

### Participant demographics

Twenty people were invited to participate. Seven people responded and 4 agreed to participate. Four semi-structured face-to-face interviews were conducted, and the main characteristics of the participants are summarized in Table 2. Participants' names have been replaced with pseudonyms. Three participants did not have thumbs and 1 was missing their index finger and middle finger. Two participants had amputations due to animal bites and the other 2 through industrial accidents. At the time, participant Edson was unable to wear his prosthesis because he had developed a neuroma of digital nerves of the involved fingers. However, he wanted to share his recent user experience.

The study found that users had different experiences with their prostheses, the 3 superordinate themes identified were:

- *Regaining 'Grip' on life supported by prosthesis*
- *Balanced load by prosthesis*
- *Tool or body part: Technical aspects of prosthesis.*

These themes are summarized in Table 3; it should be noted that these superordinate themes and main themes are interconnected. Quotes from the interviews are presented, illustrating how the themes and researcher interpretations reflect both individual and shared experiences.

### Regaining 'Grip' on life supported by prosthesis

This theme reflects participants' experiences with a digital prosthesis and the significance of the device in their everyday lives. The prostheses improved participants' quality of life, despite the fact that the prostheses are not valuable for performing all activities and are therefore perceived as suboptimal solutions.

#### Self-esteem

A missing thumb or 2 missing fingers can make it difficult or even impossible to grab and fix objects. As a result, participants felt they were limited in their ability to perform daily activities. All participants experienced their prostheses as supportive but suboptimal solutions for carrying out their activities. However, the prostheses were perceived as an important support in participants' efforts to carry out their activities independently. This independence was important for their self-esteem:

*'Yeah, not having to wait for everyone, and... if there is something wrong with the car at night that needs to be welded, then I don't .... have to wait for a mechanic who happens to be at home already. I should be able to do that by myself'. (Pete)*

*'It's just handy that they [family or friends] can indeed give something to me, to be able to tackle...' (Elynn)*

A prosthesis can also compensate for an amputated finger in a way that a person's body image can be experienced as complete. Two participants experienced their prostheses as an important part of the body that supported self-esteem:

*'Being active with grandchildren in toddler age doesn't immediately make it easier with the prosthesis, but it just feels more confident to me, more complete with the prosthesis.' (Jane)*

*'...I don't like to walk in the public without a prosthesis. I really don't like that at all'. (Elynn)*

**Table 2**Characteristics of the sample ( $n = 4$ ) of adult digital prosthesis users.

Interview ID	Jane	Edson	Pete	Elynn
Gender	Woman	Male	Male	Woman
Age	55	46	58	40
Y since amputation	5	5	5	9
Cause	Trauma; delayed amputation	Trauma; replantation; complicated course eventually resulting in amputation	Trauma	Trauma
Number of y since first provided with prosthesis	3	3	3	8
Side of amputation	Right	Left	Left	Right
Dominant side	Right	Right	Left	Left
Involved digits	Thumb	Index finger, middle finger	Thumb	Thumb
Phantom pain	Yes	Sometimes	No	No
Neuroma	No	Yes, both fingers	No	No
Prosthesis type	Active; myo-electric (since 2 y)	Active; body powered (since 2 y)	Passive; one for work; one silicone for social activities	Passive; silicone
Prosthesis wearing time per d	2 - 5 h	Up to 10 h (if no neuroma pain)	2 - 10 h	14 - 16 h

**Table 3**

Summary of the Superordinate themes and subthemes found in this study of adult digital prosthesis users.

Regaining 'Grip' on life supported by prosthesis	Balanced load by prosthesis	Tool or body part: Technical aspects of prosthesis
<ul style="list-style-type: none"> <li>◆ Self-esteem</li> <li>◆ Recognition and respect</li> <li>◆ Resume and/or restore roles in daily life</li> <li>◆ Independence</li> <li>◆ Autonomy</li> </ul>	<ul style="list-style-type: none"> <li>◆ Safe handling</li> <li>◆ Balanced physical load</li> </ul>	<ul style="list-style-type: none"> <li>◆ Material properties</li> <li>◆ Technical possibilities</li> <li>◆ Tool vs replacement body part</li> <li>◆ Adaptation</li> </ul>

### Recognition and respect

Participants wanted recognition of their loss and suffering as well as respect for making their best effort. Recognition and respect are offered mainly through ordinary daily events:

*'And everyone likes the prosthesis too, well that I have this thing and that I can do some activities with it again. They [family] see that it makes me happy, that I can do more things again ..... but a prosthesis will never take over your hand function, never... You simply lost it, you will never actually have the feeling of a real hand again and that.....no.. (Edson)*

*'My family has been through the whole process of amputation and all that, ..... And I notice very much from them that they are happy that I can do simply more anyway with the prosthesis and.....' (Jane)*

Participants also felt that it was important to receive and share recognition, and to be respected by others:

*'And [the occupational therapist] also made notes of things I invented myself to pass them on to other patients'. (Pete)*

*'I notice that people are very involved, curious ask what is that, but also interested and positive respond with - great that this is possible. I've never had a negative reaction. (Jane)*

### Restore roles in daily life

Whilst the amputation influences the execution and perception of different roles, the prostheses helped the participants restore their independence with a direct positive impact on their performance of different roles in daily life. Two of the participants felt

their prostheses helped to restore their roles in a family or relationship:

*'That they are happy that I can just do more with the prosthesis anyway and... prosthesis that I just... can return to functioning normally within in my family as a result'. (Jane)*

*'My wife works and is often home later than I, and if she is, I have to cook. Then I have to get that lid off. So yes, for those kinds of things it is terribly useful'. (Pete)*

Three participants identified their digital prostheses as crucial to their ability to perform their work:

*'But I'm a mechanic too, so... It's really while working that I think "now I need that grip." ... " I can hold it myself and can do my own work again'. (Pete)*

*'That I need one, ...eh... for my work, for small things, just for everything eh'. (Edson)*

However, the prostheses were not perceived as valuable in all activities:

*'I had to buy another bike because I had a bike with gears, there was the lever on the left, and I had to operate it with the prosthetic thumb. Which was not possible.' (Pete)*

### Independence and autonomy

Prior to the amputation of their fingers, all participants made choices and implemented their own decisions in their daily lives. They indicated that it was important to be able to carry out activities independently and satisfactorily because they were accustomed to this arrangement. Their prostheses proved to be important to their sense of independence, repeatedly mentioning being able to grab and hold objects securely:

*'.. it is useful if you have 2 hands... a pair of hands to be able to do so'. (Elynn)*

*'And, if you take something out of the closet, a cookie jar or something, you should be able to grab it, even if it is placed high'. (Pete)*

Participants indicated that they did not want to be dependent on others and desired the ability to make choices about what activities they would perform when and how they would do it:

*'Yes, to stay independent... and not have to ask another for anything'. (Pete)*

*'The useful aspect of the prosthesis is that I just... in our family can function normally again... yes'. (Jane)*

## Load balanced by prosthesis

This theme reflects the effects of using a digital prosthesis. It also illustrates how other strategies are needed to carry out daily activities with or without this tool. However digital prostheses are experienced as a valuable support in carrying out daily activities.

### Balanced physical load

Not being able to fully deploy 2 hands means that participants performed activities in different ways. Their unaffected sides usually assumed an additional load. For Jane, this issue had led to serious complaints about the physical overload of her left arm and hand. Participants felt that using a digital prosthesis reduced the danger of physical overloading. When using a digital prosthesis, Jane's complaints about physical overload almost disappeared:

*'And since it's just easier to use the right arm with the prosthesis, I have almost no complaints on my left hand. So that's a huge benefit'. (Jane)*

Similarly, Pete experienced an improved physical load when using their prostheses:

*'Yes, that is easier with the use of a prosthesis. Yes, because then you can control the key in a normal way'. (Pete)*

### Safe handling

A 2-handed grip allows people to be safe while performing hazardous work activities and household chores. This grip also assists people as they adjust their own bodies to a new position. Pete's digital prosthesis was essential in his work, as it helped him to secure tools with a high temperature or turn at high speeds:

*'It's easy to grab the grinder quickly, but if you have to hold a plate too..., it becomes rather frustrating if you can't hold it down. A grinder like that then becomes life-threatening... and you run into those kind of things... and then if you have the prosthesis, then you can hold it properly'. (Pete)*

Cooking became less challenging for Pete and Jane after they began using their digital prostheses:

*'Holding saucepans and so on, the lifting, those are things that I found quite scary in the beginning, uhm because you are working with actual boiling hot things. But that just goes very well'. (Jane)*

Elynn gained increased confidence when climbing the steep stairs of her house because her prosthesis made it possible to grab the stair railing while she lifted her groceries:

*'Yes, with the left hand, with the right hand I then grab the handrail'. (Elynn)*

## Tool or body part: Technical aspects of prosthesis

The additional value of a digital prosthesis is determined by the purpose of the prosthesis, either an active function in the sense of grasping or a passive function in completing of body image. This theme highlights the possibilities and limitations of digital prostheses participants experienced from different perspectives. A prosthesis can be seen as an artificial tool that serves as a partial replacement for a lost body part. The material properties and technical possibilities of a prosthesis limit its ability to replace a body part. Because a silicone prosthesis did not meet their use requirements, 3 of the 4 participants received a supplementary second prosthesis. Participants experienced limitations directly related to

the material properties and technical possibilities of their prostheses:

### Material properties

The silicones used for digital prostheses are sometimes not rigid enough to accommodate the high amount of force that is released in the execution of some activities.

*'You can't just use the same force, that wasn't what struck me immediately'. (Pete)*

Pete's second prosthesis was a passive (non-movable) thumb made of stiffer materials than silicone. This second prosthesis did not distort when he exerted more force:

*'I have it mainly for grip. That is the most important thing because there are a lot of things you can't do without prosthesis. That is actually the whole idea of it all, and if you have heavy work, then you will just need to have a second prosthesis'. (Pete)*

The material properties of silicone make it possible to achieve a lifelike appearance and close fit to the hand. However, Elynn found that her silicone prosthesis was prone to wear due to frequent use:

*'And I also accepted it as part on the deal that I would have to have a new one once in so many years'. (Elynn)*

Because of the delicateness of the silicone, Elynn tended to avoid certain activities while wearing the prosthesis or switch to an older one:

*'My prosthesis is quite prone to wear... because chlorine does have quite an effect on the silicones... then I pick one that is allowed to be affected'. (Elynn)*

### Technical possibilities

Digital prostheses made of silicone cannot move, as the position of the finger is fixed. As a result, the grip range of a hand is smaller, and manipulating objects is more difficult.

*'You do the movement with your finger, of course, you can't move the prosthetic thumb'. (Pete)*

*'A carton of milk, then it becomes a bit trickier'. (Elynn)*

Edson and Jane's second prostheses were active ones with greater mobility that made it possible to grab and hold objects more successfully:

*'Uhhh, well this prosthesis is a tool for... to be able to have a slightly better hand function'. (Edson)*

*'I can grab things ..... more easily because it being movable, that prosthesis... uh... whether it's coarse grip work or fine grip work... uh... Yes, I can perform certain actions better'. (Jane)*

Both Jane and Edson encountered limitations with their active digital prosthesis. At first, Jane had to learn to rely on the mechanics of the prosthesis:

*'Lifting, that I found quite scary in the beginning'. (Jane)*

Jane then realized that the electrical driven digital prosthesis had to be protected from moisture to prevent the electric drive from short-circuiting:

*'That depends on what I am going to do. When I go into the garden, and the earth is wet and muddy, then not'. (Jane)*

Edson discovered that active digital prostheses have limitations in range of motion and the exertion of great force:

*'I had expected more, more bending functionality and to be able to do more small things yes'. (Edson)*

#### Tool or replacement body part

Some participants sought a reliable tool with which they could clamp and grip objects firmly. Others sought prostheses with a life-like appearance to replace their fingers. Participants experienced their digital prostheses as valuable tools with which they could carry out activities:

*'For me, it is primarily a tool, it is not that I am ashamed that I have no thumb, most people do not even notice'. (Pete)*

*'But, such a prosthesis will never replace the function of your hand, never. You've just lost it, you'll never have that feeling of a real hand again'. (Edson)*

Elynn's prosthesis was particularly valuable for restoring both her hand function and her self-image:

*'For me, it has to function well enough to do the basics, for the basic things during the day.' (Elynn)*

*'The value of the prosthesis is big, because that is.... yes..... that's the self-image you radiate to the other. One just sees you.... Most people don't know it's a prosthesis. They always ask first....and look at it... yes ....Okay, ....and then it's very beautiful, really cool.... and yes..... then there is positive talk about it.' (Elynn)*

#### Adaptation

None of the participants felt that their prostheses completely replaced their lost fingers. It does not replace original hand function, and it was still necessary to adapt either performance of activities or the environment:

*'... only a bike handlebar is also too thin'. (Edson)*

*'You just can't hold it. I have had to buy a custom drill, which is suitable for use with the prosthesis. At first, I had a drilling machine, which I even couldn't even hold. So you can't actually do without a work prosthesis anyway'. (Pete)*

#### Discussion

All the participants in this study used a prosthesis, and 3 had each worn different types of prostheses. The devices helped participants engage in daily life by contributing to independent occupational performance and restoring the ability to fulfil different roles in their lives related to self-care, work, family, relationships (partner), and social activities. Restoring life to what it was before their amputation was important for the participants and was being helped by using their prostheses.

The goal for use of a prosthesis determines the requirements a prosthesis must meet, though the technical possibilities are not always sufficient to achieve these requirements. Their prostheses had different meanings for each participant, but similarities as well as differences were identified in their accounts. All participants felt that it was important to live independent lives, and their prostheses played an important role in helping them achieve independence.

#### Digital prosthesis use

Digital prostheses were used to restore body image and/or hand function. One participant (Elynn) valued her prosthesis because it restored both hand function and body image. This is supported by

studies about user experience of arm prostheses, where the recovery of body image and/or hand function also emerges as an important theme.<sup>4,22,23</sup> All participants in the current study wanted a prosthesis in order to be able to perform activities independently but encountered factors that both impeded and encouraged their use of a prosthesis. They started with passive silicone prostheses that improved both appearance and function. Three participants had digital prostheses for functional use. One participant (Pete) used 2 prostheses: 1 to improve functioning and 1 for social occasions. Studies show that the purpose of a prosthesis can change for patients over time. Initially, a prosthesis can be of great value as psychological support in learning to cope with the new situation.<sup>12,13</sup> But also in many cases, a single prosthesis does not satisfactorily fulfil user needs and multiple prostheses are needed to perform various activities.<sup>24</sup>

Biddiss and Chau<sup>25</sup> suggest that if prostheses were well used, those prostheses were often worn 5-16 hours per day. The findings of the current study suggest that whether or not a digital prosthesis is used to perform an activity is guided by users' expectations and users' experiences on prosthesis applicability.

#### Regaining 'Grip' on life supported by prosthesis

All participants indicated that the amputation of their fingers made it more difficult to grasp, hold, and manipulate objects. They felt they were dependent on others to perform activities or important roles. This issue had a negative impact on participants' autonomy and independence. Although participants were thankful for any help offered by family and friends, they wanted to do activities without help from others. Amputation of fingers is a permanent disability that necessitates a renewed reflection on the goals and values of life, but also to find a different way of life as desired.<sup>26</sup> Autonomy, self-determination, and responsibility for their own lives were important values, with participants wanting the freedom to decide whether or not to ask for help. Hammel et al.<sup>27</sup> describes autonomy as a construct of 2 parts. On the one hand executive autonomy or the ability to act as one wishes and, and on the other hand, decisional autonomy, that is, the possibility of making choices and controlling own life and acting.<sup>27</sup> Participants in this study seem to experience mostly problems in their executive autonomy.

Participants' digital prostheses improved their grip, and this improved grip allowed them to perform important activities themselves. Their prostheses made it possible to perform 2-handed tasks in different areas of daily life, such as self-care, household, work and social occasions. Having the ability to grip more effectively is a prerequisite for having grip on life. For all participants, independence in self-care, significant relationships and the resumption of work (both paid and unpaid) were important, and their prostheses made this possible. For all participants, independence in self-care, significant relationships and the resumption of work (both paid and unpaid) were important, and their prostheses made this possible through enabling them to grip more effectively. This supports the findings of Murray,<sup>4</sup> that being able to perform important roles independently again is of deep personal significance to upper limb amputees. Use of a digital prosthesis makes it possible to carry out more activities independently, this improved executive autonomy contributes to the identity, self-esteem, and roles that fulfil the individual values.

Regaining a positive sense of identity and being able to equally contribute to various relationships and situations in life helps participants feel that their quality of life is similar to what it was before their amputations. Digital prostheses helped the participants to regain their self-esteem and identity. A similar result with hand prostheses had been found in the studies of Murray and Forshaw<sup>28</sup>

and Wijk and Carlsson.<sup>23</sup> Use of their digital prostheses facilitated participants' efforts to have a meaningful existence. Cardol et al.<sup>26</sup> found that it is important to have the ability to make free and independent choices to shape life into a meaningful existence.

In the current study, the appearance of a digital prosthesis was of such significant value for Elynn's self-esteem that she would not leave her house without wearing it. None of her friends or family had seen her hand without the prosthesis; she only shared her naked hand with health professionals. In his study of understanding the lived experience of prosthetics use for amputees and people with congenital limb deficiency, one of Murray's<sup>4</sup> findings were that a realistic appearance of the prosthesis was frequently described as of personal value to users. The realistic appearance of a prosthesis was considered to help a person's psychological health and well-being, and therefore preferable to the usefulness of a functional prosthesis.<sup>4</sup> A prosthesis can help someone to pass as normal in daily life, by diverting attention from amputation. Hoogsteijns and Van Der Horst<sup>29</sup> states that an arm prosthesis, through its presence or absence, changes one's possible social strategies and responsibilities in dealing with being different. It has been found that the use of a lifelike silicone prosthesis protects a person's body from the values of a society that views the disabled as less valuable and inferior to those viewed as normal.<sup>30</sup>

#### *Load balanced by prosthesis*

In the present study, Jane had severe musculoskeletal complaints (MSCs) of the contralateral side due to unevenly distributed loads across her body, and a digital prosthesis was recommended to her to relieve the contralateral side. The MSCs diminished when Jane started to use her prosthesis, and this improvement became the main reason she used the device. Clinically, a prosthesis is seen as a tool to support balance and body posture while people independently complete activities. There is limited research into overuse injuries in individuals with upper limb amputations, particularly in partial-hand amputations it has been estimated that up to half of these individuals may experience MSCs.<sup>31,32</sup> In the study of Wanamaker et al.<sup>33</sup> 4- and 5-digit limb loss participants experienced more severe and awkward joint movements without their prosthesis. In this way, a prosthesis can prevent uneven distribution of a load across the body and a reduced risk of overload resulting in MSCs.

Previous studies have shown that MSCs are usually localized in the contralateral side.<sup>32,34-36</sup> Research on MSCs due to upper limb amputations (ULA) found that 50%-65% of samples examined had complaints.<sup>32,35,36</sup> However, no relationship has been found between wearing a prosthesis and presence of pain.<sup>32,36</sup> Bouma et al.<sup>34</sup> found that individuals with finger or partial hand amputations reported fewer MSCs than people who had received upper limb amputations at the wrist or proximal to the wrist level. Bouma et al.<sup>36</sup> also found that 37% of the sample experienced MSCs compared to 33% of the control group. The physical disability of a finger or thumb amputee with a normally functioning wrist joint is not as great as for ULAs, which then leads to a lower probability of MSCs.<sup>36</sup>

#### *Tool or body part*

What people want from a prosthesis varies. Jane and Elynn used their prostheses daily because they felt complete while wearing and using the devices. Pete and Edson viewed their prostheses as vital tools for performing daily activities. Unlike the other 3 participants, Elynn was not able to function or participate without her prosthesis. She spoke emotionally about being unable to leave the

house without her digital prosthesis, and she viewed the prosthesis as an essential replacement for her thumb. The study by Wijk and Carlsson<sup>23</sup> showed that people don't want to stand out in the social environment, don't want to draw attention to their physical differences. Appearance is an important factor as a cosmetic prosthesis was the first choice of new amputees.<sup>4,23</sup> A prosthesis with a lifelike appearance is preferred over a functional prosthesis when a person needs support for their psychological health and well-being.<sup>4,25</sup>

All participants started with digital prostheses made of silicone. Silicone prostheses have the appearance of a finger, but they cannot flex and extend like a finger. This makes it difficult to grab small objects; this problem discouraged Pete and Edson from using their prostheses at work. Other studies of hand prostheses have found similar problems, such as the lack of a reliable grip and difficulty performing activities.<sup>23,37</sup> These studies also report that hand prostheses are perceived as clumsy and prosthesis users are limited in their professional performance.<sup>23,37</sup>

#### **Limitations**

This study provides valuable insight into the experiences of digital prosthesis users; however several limitations may have impacted on the findings. Qualitative research seeks not to generalize information but to identify what a group of individuals have in common.<sup>18,19</sup> One risk of working with a sample from a population is that a study using a different sample from the same population can produce different results.<sup>21</sup> The sample was a small group of digital prosthesis users who fit a specified sample frame. This choice makes it difficult to generalize the findings to all users of digital prostheses. Although the study aimed to recruit eight to ten participants only 4 subjects were recruited. Furthermore, the ratio of thumb to finger amputees was 3-1. These factors combined may have resulted in potential for response bias and sample error.<sup>21,38</sup>

The participants in the study were all of Dutch descent, this homogeneity may have biased the findings, and it is likely that the sample is not representative of the centers' population of digital prosthesis users or the wider population. The sample was heterogeneous in several areas, including type of prosthesis used, cause of injury, life phase of the participants, fingers involved. These differences may have affected the outcomes.

Despite the request to consider the interviewer as not experienced in the field of prosthetics, it may be that participants' assumptions about the researcher's knowledge were incorporated in their stories. As a result, participants may have shared less information than they would have shared with a person with little or no experience in prosthetics. In one case, the researcher was also the practitioner, what might have led to assumptions (or interview) bias.

The researcher's experiences may have biased the way in which the findings were processed, as she may have examined the text with unconscious assumptions. Regularly reflection both with and without the second author on the process was applied to minimize these unconscious assumptions. Peer review was not carried out and this may have impacted on the rigor of the findings.

As the participants used the department's care and services, it is possible that they gave socially desirable answers. Due to this arrangement, the interviewees may have an economic, and emotional interest in participating in this research.

#### **Conclusions**

This study explored the experiences of digital prostheses in users' daily functioning. For amputees it is important not only to retain their identities but also maintain self-management of their

own capabilities. Autonomy in completing activities was a common theme among the participants. Participants felt that it was important to live independent lives, and their prostheses played an important role in helping them to achieve independence. These devices can also help to restore body image, when affected by amputation.

Findings suggest that the digital prosthesis is perceived as a valuable tool to resume the life of before the amputation. Use of a digital prosthesis replaces post-amputation dependency with a sense of autonomy and freedom.

The main finding of the current research is that digital prostheses are perceived as important for independent performance and participation in society. The devices enabled the participants to perform important occupations independently and take part in domestic, work and social activities. Over time, the need for a digital prosthesis may change, and a different type of device may be needed. In the clinical setting these findings are recognizable. The findings of the current research help practitioners in advising the client regarding the most appropriate digital prosthetic to meet their needs. The findings from this study may be used to inform future studies, in particular with larger sample sizes.

## Appendix A. Interview schedule

### Welcome

Brief introduction to researcher and the project

- Reminder that participant has given consent to participate and for the interview to be recorded and check whether they are willing to continue
- Researcher's working life and interest in hand therapy
- MSc hand therapy final module
- The researcher's special interest in amputations and prosthetics

### Demographic items

- Age, year of trauma, cause of trauma, year of first prosthesis fitting, site of amputation, dominance, included digits, phantom pain, neuromas, type of prosthesis (passive and/or active), and wearing hours of prosthesis.

### What has brought you to use a prosthesis?

- Tell me about how you obtained the idea for a prosthesis.

### Tell me about your daily life using a prosthesis

- Tell me about carrying out self-care activities or household tasks
- Tell me about doing sports or leisure activities
- Tell me about performing work-related tasks or volunteering
- Tell me about cycling, driving a car, public transport

### How did you find doing these activities without a prosthesis?

- Tell me about carrying out self-care activities or household tasks
- Tell me about doing sports or leisure activities
- Tell me about performing work-related tasks or volunteering
- Tell me about cycling, driving a car, public transport

### Tell me how the prosthesis is of intra-personal value for you as person

- Tell me about what it brought you as person
- Tell me about the value for you when you are with your family at home
- Tell me about the value for you when you are in community
- Tell me about the value for you when you are at work or volunteering

Tell me how the prosthesis is of inter-personal value for you as person

- Tell me about the value for you when you are with your family at home
- Tell me about the value for you when you are in community
- Tell me about the value for you when you are at work or volunteering

Thank you very much for participating in this interview.

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