BEYOND FUNCTION: USING ASSISTIVE TECHNOLOGIES FOLLOWING LOWER LIMB LOSS

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Objective: To explore how individuals experience and perceive the use of assistive technologies following lower limb loss.

Design: Cross-sectional qualitative interview design.

Patients: Thirty individuals with lower limb amputation were recruited from a multi-disciplinary rehabilitation programme (26 males and 4 females); comprising individuals with above-knee (n = 16), below-knee (n = 12) and bilateral (n = 2) amputations. Patients were at least 15 months post-rehabilitation, at least 18 years old and spoke English.

Methods: Semi-structured interviews were conducted via telephone or in person. Interview data were inductively thematically analysed by a researcher who had no previous contact with participants.

Results: Three key themes were identified: “It didn’t feel part of me” – Heightened awareness and experiences of distance from prostheses following lower limb loss; “Depending on others is really tough” – Independence through assistive technologies; and “I feel confident with this leg” – The value of prosthesis use following amputation.

Conclusion: The findings demonstrate that individuals with lower limb loss perceive and experience assistive technologies to have uses in ways beyond their potential for functional restoration. They may also attribute meanings and values relating to such technologies that may influence their use. Ascertainment and being aware of individuals’ experiences and perceptions of assistive technologies is important for lower limb loss rehabilitation.

Key words: lower limb; amputation; assistive technology; qualitative; independence; embodiment.

INTRODUCTION

Individuals with lower limb amputation (LLA) face a variety of physical challenges, including mobility limitations (1) and environmental barriers (2). These challenges can prevent individuals from performing valued daily activities (3) and may hinder their psychological and social adjustment to limb loss (4). In addition, individuals with LLA are often dependent on others for their basic needs following surgery, frequently relying on family members for transportation (5), or assistance from others to perform everyday activities (4), which can bring about feelings of disempowerment and symptoms of depression (6). In order to overcome these challenges and restore mobility, assistive technologies (ATs; e.g. prostheses, wheelchairs and vehicle adaptations) are typically incorporated into post-amputation rehabilitation as appropriate to the person’s needs (7). These technologies augment functional capabilities (8), facilitate performance of everyday activities (9–10), and aid in the individual’s participation in their environment (11–12); key factors that are thought to enhance well-being in conceptual models of rehabilitation, such as the International Classification of Functioning, Disability and Health (ICF; 13). With regard to LLA, mobility devices such as wheelchairs and prosthetic limbs enable many individuals to increase their functional capacities following their limb loss and in the longer term (7, 14). Wheelchairs (7) and prostheses (15–17) can also help individuals to complete daily tasks more independently; a primary objective of AT implementation (4). These attributes make ATs valuable components of the LLA rehabilitation process.

In spite of these benefits, individuals with LLA do not always regard ATs as sufficient resources for improving their functional capacities. For instance, they may be disappointed with limitations of their prosthesis (18), or find that prosthetic use interferes with their professional life (19). In addition, many experience pain or discomfort, which inhibits their prosthesis satisfaction (7, 20–21). Wheelchairs have also been found to be limiting among individuals with mobility impairments such as those with LLA, as these individuals often require continued dependence on others for transportation and everyday tasks (22). Dissatisfaction and disappointment with ATs can also lead to device abandonment (7, 21).

These findings point towards a need for further clarity regarding experiences and perceptions of using ATs following LLA in order to inform rehabilitation. In particular, while a central goal of AT implementation is to restore functional capacity (23), it is important to establish whether individuals’ own experiences and perceptions of such technologies extend...
METHODS

Study design and data collection methods

Data were collected via semi-structured interviews composed of a series of open-ended questions; participants were encouraged to discuss their current goals, how their limb loss affected or changed their goals, new priorities that had emerged for them since their amputation and their current goals, how their limb loss affected or changed their goals, series of open-ended questions; participants were encouraged to discuss.

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Data analysis

The inductive thematic analysis of the data followed a model outlined by Braun & Clarke (29). This involved an initial process of data immersion, followed by a coding phase where pertinent features of the data were identified and appropriately coded. These codes were then examined independently in order to purposefully identify themes. Themes were related back to the coded data extracts to ensure they made sense and formed a coherent pattern. Themes that did not fit well with the data or did not have enough data attached to them were discarded at this stage. The final stage of the analysis involved identifying the essence of the themes and clearly defining and naming them. To reduce potential bias, the data were thematically analysed by the first author; an independent health psychology researcher with an interest in AT who was not affiliated with the rehabilitation programme and had no previous contact with participants. The credibility of the findings was enhanced by 3 of the authors (LC, DD, PG) who validated the interpretation of the analysis by cross-checking the quotes and themes.

RESULTS

In the following analysis, names have been changed in order to preserve anonymity. Three key themes relating to participants’ experiences and perceptions of AT following LLA were identified. These themes are presented below together with excerpts from participants’ actual discourse. Ellipses are used to represent words missing from quotations.

“IT didn’t feel part of me” – Heightened awareness and experiences of alienation from prostheses following lower limb loss.

Some participants experienced heightened awareness of their prosthesis through pain, discomfort or lack of balance. Such experiences often led participants to feel alienated towards their prosthesis, and this manifested in the language they used. For example, prostheses that were perceived to be ill-fitting or caused discomfort were commonly objectified by participants. In such instances, participants typically referred to their prosthesis as “the leg” rather than “my leg”; suggesting that they felt alienated towards it. Such experiences highlight how prostheses may be perceived in negative terms that do not explicitly relate to their functional capabilities. For instance, Seamus [BKA, age 80 years], had heightened awareness of the prosthesis, and used objectifying language to describe his prosthesis as opposed to his “own 2 legs” from before his operation:

I do have a bit of a problem with the leg sometimes. If you are walking and it is not on right it will give you a bit of bother, but you know you have it, it is an inconvenience, you’d be better with your own 2 legs.

Another participant, Keith [BKA, age 70 years], highlighted this disconnection between his prosthetic leg and his body when describing difficulties he encountered when trying to make his prosthesis feel comfortable.

The leg I have now is pretty loose-ish, which means I need more stockings. [...] I’ve reached a stage now where I know I’m not going to go any further [with the prosthesis] and the worst problem that I find is an inability to do jobs I used to.

In this way, perceptual awareness and feelings of alienation from a prosthetic limb could be seen as integrally linked phenomena. Participants also indicated that such alienating experiences led them to appreciate the importance of feeling that a prosthetic limb was part of their body. Terrence [AKA, age 42 years], outlined this point when he recounted his experiences with a prosthesis that he perceived to be ill-fitting.
He described how his increased awareness of this prosthesis, arising from perceptions of discomfort and inappropriate fit, ultimately resulted in feelings of disconnection between the prosthesis and his body and inhibited his ability to carry out work-related tasks.

[My original] prosthetic leg, I don’t think was up to scratch for what we were doing. […] It should fit like a glove and the way I felt with the stump going into that socket, it felt like it was going into a bucket. […] And when I go up and I do a bit of work around the farmyard, doing the bare minimum around that farmyard and I’d have to come home and take the leg off. It just didn’t feel comfortable, it didn’t feel part of me. […] The socket definitely should have fit me more securely, more properly. Not more securely but even with the belt around it everything was just feeling so cumbersome and it just didn’t feel part of you. And I felt if I was like that I’d be an old man within no time.

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The independence provided by adapted cars was regarded as particularly important by many participants in adjusting to their limb loss. An adapted car allowed many participants to overcome their loss of mobility and functional dependence by giving them the capacity to travel unaccompanied. Alfred [AKA, age 54 years] described how his adapted car allowed him to reclaim his own sense of independence and freedom, which he had lost after surgery.

When I got the car I was a year and a quarter without being able to do anything when I was in a wheelchair and before I went into the [rehabilitation institute]. [The car] gave me independence — being able to get around. […] Certainly the transport has enabled me to get to things and do things like that. Before, which I wasn’t able to do in the immediate aftermath.

In contrast, participants who did not have an adapted car perceived their sense of agency as somewhat more restricted. For instance, Shane [BKA, age 46 years] described how his inability to drive had inhibited the pursuit of one of his most valued activities; “The fact that I don’t have a car [makes it difficult to get to football matches]”.

Participants also described how they had experienced significant dependence on friends and family members following surgery. For instance, Linda [BKA, age 40 years], described how her inability to drive immediately after her amputation contributed to feelings that she was dependent on others for support. She suggested that knowing she would be able to drive in the future (i.e. by having her car adapted) allowed her to come to terms with this temporary lack of valued autonomy.

Well I had to give up my independence for the first 6 months and I think that was probably the hardest thing for me, having to rely on other people for everything and having to
give up driving. That was a major big deal to not be able to go where I wanted to go when I wanted to do it. And to be depending on other people, I found that really, really tough. I told myself that it was a temporary thing and that I would get back driving again and I would get my life back.

Another aspect of autonomy that car adaptations provided was freedom of choice. In this regard, 1 participant, Christopher [AKA, age 70 years], suggested that the variety of car adaptations available meant that he could choose the extent of technological adaptation necessary to suit his particular condition; thereby endowing him with a degree of freedom and a sense of control.

I’ll get a new car when I get the prosthesis. [...] I’ll get an automatic [car]. I’ll get one which I can just use the right leg, ‘cause that’s all you need’. There’s one pedal only or I can get all the controls up on the steering wheel. [I’ll get] whatever I fancy.

As with adapted cars, being fitted with a prosthesis also enabled functional independence and provided a sense of autonomy for participants. For instance, 1 participant, Donal [AKA, age 69 years], highlighted how his prosthesis had given him both increased ability to overcome his functional limitations and freedom from the dependence and confinement of the hospital setting.

Honestly, the prosthetics and all this and all that, it doesn’t worry me anymore, I can get around. There is nothing stopping me. I can go in and have a pint and watch a football match on telly, there is nothing that I can’t do. Where going back I hadn’t got the prosthetics and all, I was just thinking “What am I going to do?” Because it was all “hospital, hospital” to me. I was sort of institutionalized; it was all I knew for 8 months, was doctors and nurses, that was without a break.

In this way, prosthesis use provided mobility as well as a sense of freedom and autonomy. In contrast, a prosthesis was perceived to be less useful if it did not provide functional independence or greater autonomy. For instance, Joanne had been fitted for a prosthesis, but required the supervision and assistance of others to use it and felt more able without it. As such, she did not perceive the prosthesis to have value.

The prosthesis leg, that’s a problem. [...] They told me in the rehabilitation that I’d never be able to go out in the street with it so what is the point in having it? I can do more without it. [...] We asked, like “the daughter is three doors away from me” and “Could I go out to her?” and they said no, unless there was someone walking in front of me, and I use a Zimmer frame, and someone walking behind me. [...] That money that is getting spent [on the prosthesis] could be spent on someone else because I know I can actually do more without it.

For some participants, wheelchairs provided increased mobility and the capacity to perform most of their daily activities. One participant, Rupert [AKA, age 73 years], described this process explicitly:

Mostly I can do without the limb; I can do it in the wheelchair. The only thing I can’t do is shower, I have to get somebody, well I nearly could do it on my own but I would want somebody to get the water to the right cold and hot. But most of it I can do.

Nonetheless, other participants indicated that wheelchairs inhibited their autonomy and functional independence following surgery. For instance, Christopher described how he was reliant on other people for transport due to his wheelchair use. [I’m more limited] just really to get around and get out when I want to get out and I have – I get an ordinary taxi over to the pub. But going over to [the hospital] for a check-up or anything like that, I get my wheelchair taxi. He’s another friend of mine. I just give him a ring – but otherwise everything is going fine.

Wheelchair use also represented confinement to participants who were regular prosthesis users. For instance, Dermot described how he felt he was better off than other people he had met who had undergone LLA, but were confined and restricted by their wheelchair use.

I can’t run but I can get around the place, particularly with my car so I have no complaints and I know that I am an awful lot better off than a lot of my peers who have had similar operations and they are confined to their wheelchairs, confined to their houses. [...] I met one just before coming out here, he was in the bed beside me in the hospital and he is still in his wheelchair 3 years after leaving. I came home in my wheelchair and put it in my garden shed and it has been sitting there ever since. I have not sat in my wheelchair since I went home [from rehabilitation].

“I feel confident with this leg” – The value of prosthesis use following amputation

Participants indicated that successful use of prostheses helped them to overcome the substantial physical and psychosocial challenges they faced following LLA. In this respect, prosthesis use provided participants with a range of values beyond their functional capabilities, which were often highly individualized. Firstly, many participants noted that their prosthesis had provided them with a meaningful goal to work towards in spite of their limb loss. One participant, Daniel [AKA, age 70 years], described how the prospect of being fitted with a prosthetic leg gave him a goal to work towards following surgery, providing him with a newfound sense of purpose.

Well now all my efforts are concentrating on living life still to the full, enjoying it as much as possible and doing as much exercise as I can so that I will hopefully get a prosthesis.

Participants also indicated that seeing others at various stages of rehabilitation was a source of inspiration, enabling goals of successful prosthesis fitting and adoption to materialize. For instance, Linda, who had experienced depression following limb loss, suggested that seeing others at various stages of rehabilitation had inspired her to overcome pessimistic thoughts surrounding her functional abilities and provided a context for the goal of prosthesis fitting and adoption to manifest itself. When you are going in [to rehabilitation] and you don’t have a leg and you don’t know what to expect and you meet other
people who are at the end of their rehab and you see them and they have been fitted with the limb and they are walking. Or you see somebody one day and they are in a wheelchair and a couple of days later they are up on a walker, another couple of weeks and they have progressed to a walking stick. So it is really uplifting for you personally to see other people progressing with their rehab because it means – I didn’t think I could do something and now I can see somebody who I thought was in a bad way, look at them now 3 weeks later, they are up and walking.

In addition to providing a goal to work towards, many participants suggested that prosthesis fitting and adoption had inherent value beyond functional restoration. In particular, the prospect of being fitted with a prosthetic limb provided a sense of comfort in the knowledge that one might be able to walk again. Terrence, whose leg was amputated following a serious construction accident, described how this sense of comfort allowed him to overcome the loss of his leg. The evening after the accident, I knew the leg was gone, I knew I could get a prosthetic and well maybe next best scenario, maybe they can sew the leg back on, maybe there is not that much damage done to it. I didn’t know. You often hear of miracles. I said, to hell with it, if that doesn’t work I’ll have a prosthetic anyway, I will get walking again.

Terrence also described how the confidence attributable to his new prosthesis had provided him with a renewed sense of enthusiasm.

Now I feel confident with this leg that I can go anywhere, do anything I want with it. In this way, the knowledge that a prosthetic limb could act as a replacement to the lost limb may provide individuals with a sense of comfort and renewed vigour following amputation. The importance of walking was also considered to have value for other individuals who had undergone LLA beyond its functional role in allowing one to get from place to place. These participants expressed a sense of relief at the prospect of performing this everyday activity.

Seamus: That was one thing when I was in there too, just to be able to walk. I wouldn’t walk great distances now but I walk just where I want to, I walk out of the car or walk into the church or walk into a hotel.

Other participants suggested that their prosthesis had value in providing them with a newfound feeling of confidence. Frederick [BKA, age 67 years], who had recently been fitted with a below-knee prosthetic leg, described how it had given him a sense of purpose; allowing him to see himself as a useful person.

Well, since I had the surgery and I got the leg it has given me like I can do something. […] It has [given me a bit of confidence], of course yes. The leg was a good job.

**DISCUSSION**

This study demonstrates that, following LLA, individuals’ experiences and perceptions of ATs extend beyond the functional capabilities of these devices. While participants indicated the potential for ATs to restore functional mobility, they also described how their experiences of independence with ATs related to their autonomy-providing potential. Participants also singled out personally meaningful values associated with prosthesis use, such as the sense of purpose, enthusiasm and appreciation of the importance of walking that prostheses provide; indicating prosthesis-related concerns that extend beyond its functional potential. Furthermore, the findings suggest that heightened awareness and alienating experiences towards prostheses may be related to ambivalence towards prosthesis use.

A key finding concerns how participants sought independence through ATs differentially in relation to their functional capacities and autonomy-providing potential. This supports the work of Sousa et al. (6), who suggested that independence for individuals with amputation consists of 2 distinct dimensions; mobility, which relates to one’s ability to get around and perform everyday activities, and freedom/autonomy, which relates to the notion that one is an autonomous agent. The current findings extend this work from prosthesis use alone to the use of other ATs, such as wheelchairs and adapted cars. Participants in this study perceived adapted cars as enabling ATs, which allowed them to travel unaccompanied and provided them with freedom of choice and a sense of autonomy. The findings also support research that shows that prosthesis use represents an effective way of achieving autonomy following LLA (18, 30). In contrast, despite their potential to provide increased mobility, wheelchairs were often seen to inhibit autonomy due to increased dependence on others for transport and their seemingly confining and restrictive nature. This accords with research reporting that wheelchair use requires a degree of dependence on others for transportation and everyday assistance (22). Taken together, these findings suggest that Sousa et al.’s (6) conceptual dichotomization of independence may be particularly useful for understanding the perceived impact of ATs on people’s sense of independence following LLA. Distinguishing between perceived autonomy and enhanced mobility may also be of particular value to models of illness and disability, such as the ICF. For instance, studies using the ICF as a framework for measuring individuals’ well-being following rehabilitation have incorporated measures such as the “Impact on Participation and Autonomy Questionnaire” (e.g. 31–32), which operationalize the construct of autonomy as a combination of enhanced mobility and freedom of choice in relation to an individual’s participation and pursuit of everyday activities. In contrast, dichotomizing these potentially discrete aspects of independence in line with Sousa et al.’s definition (6) may enhance the predictive value of this construct in relation to outcomes such as individuals’ participation and performance of activities of everyday living. As such, there is scope for the development of a measure that differentiates between these 2 aspects of independence in future research.

Participants also indicated that prosthesis use gave them a meaningful goal to work towards following LLA and had significant value beyond the restoration of functional loss. Several participants revealed that the prospect of prosthesis use gave...
them a renewed sense of purpose in the post-operative period, a tangible goal to work towards, which was invigorated by seeing others successfully accomplish successive stages in their prosthetic rehabilitation. The goal of prosthesis adoption also had value for these participants beyond functional independence, by providing an emotional catharsis, sense of comfort and emotional respite in the face of losing a limb. Participants also suggested that their prosthesis had value in providing them with renewed confidence and enthusiasm. Walking was also seen to have value in itself; participants expressed relief at the prospect of being able to perform this everyday but fundamental activity. This supports Murray’s (33; p. 576) findings that a prosthetic limb can act as a “life-enhancing tool” by allowing an individual with an amputation to “get their life back together” through the restoration of activities such as walking.

A particularly unique finding of this study relates to the alienating experiences that some participants had towards prostheses in occasions where they felt pain, discomfort or lack of balance arising from the prosthesis. Where they occurred, such experiences elicited a language of disassociation from participants in relation to their prostheses. The use of this language was associated with ambivalence towards prosthesis use and, in some instances, abandoning the prosthesis. Due to the similar language used in describing their site of injury, the alienating descriptions of participants in this study may be likened to Morse & Mitcham’s (34) findings of “disembodying” language used by burns victims in relation to their afflicted body parts. MacLachlan (35; p. 28) also reported a similar use of such language by a young woman towards her foot, which she was preparing to have amputated. Morse & Mitcham argue that such disembodied language is an attempt to retain the integrity of self (34; p. 671). In the current context, this may mean that individuals strive towards experiencing their body as an integrated whole following LLA, and feelings of prosthesis awareness that conflict with this unified body may contribute to a sense of distancing or alienation from prosthetic technologies.

Participants also indicated that they had become more aware of the importance of feeling that their prosthetic limb was part of their body through its dysfunctional appearance in their perceptual experiences. Such experiences relate strongly to the “dys-appearance of the body” (i.e. the emergence of embodied experience through dysfunction) described by Leder (36), who proposed that disability or dysfunction interrupts our normal unawareness of our bodies, thereby highlighting what constitutes our normal sense of embodiment or incorporation. In these instances, the body moves to the foreground and our voluntary thought, systems of meaning and grip on the “world of experience” recede into the background (37). In the context of prosthesis use, an artificial limb may move to the foreground during experiences of heightened prosthetic awareness, such as pain, discomfort or lack of balance. The current findings also demonstrate that a prosthesis that “fits like a glove” may be more readily incorporated or experienced as part of or an extension to an individual’s body, thereby encouraging them to continue to use their prosthesis. Such ideas support emerging research in the area of prosthetic embodiment suggesting that prosthetic rehabilitation should aim to achieve a sense of bodily incorporation of the prosthetic limb (38–39) and extend them by demonstrating that a prosthesis that is not seen as part of one’s body may lead to feelings of alienation towards it; experiences that may contribute to prosthesis abandonment.

This study had a number of limitations. The cross-sectional design could mean that findings only relate to adoption of ATs by individuals with LLA with a mean of 15 months after completing rehabilitation. Future longitudinal qualitative research could establish whether or not such individuals continue to perceive mobility devices and other ATs in the manner described in the current study. The findings might also not be generalizable to other forms of functional disability, which can differ in both the type of AT and degree of AT engagement involved. Data collection was not specifically designed to investigate the experiences and perceptions of individuals with LLA in relation to AT. Consequently, future research, which explicitly incorporates such topics in the data collection phase could help to further elucidate the findings described here. Nonetheless, the fact that participants spontaneously discussed their experiences and perceptions of AT suggests that this data reflects important issues and concerns for individuals with LLA. These findings have also helped to generate new ideas for this field; specifically how “prosthesis disembodiment” is experienced, how prosthesis-related meanings and values can be highly individualized, and how independence is experienced through particular ATs. Finally, although the second author’s prior contact with participants may have influenced their responses during interviews, analysis was conducted by an independent researcher, thus enhancing the trustworthiness of data interpretation.

The above findings have a number of important implications for future research and rehabilitation following LLA. Firstly, the novel findings concerning participants’ experiences and perceptions of AT may be considered as important “personal factors” in relation to the well-being of individuals with LLA (in line with the ICF; 13). Future research could explore the relative impact of these personal factors on the performance of and participation in valued everyday activities by individuals with LLA using the ICF as a conceptual model. The current findings suggest that Sousa et al.’s (6) conceptual division of independence into dimensions of mobility and freedom/autonomy may be a particularly useful way of understanding the perceptions of individuals with LLA in relation to ATs. This conceptual division may also aid in the promotion of ATs in this patient group. For instance, rehabilitation professionals could emphasize the potential for prosthetic devices, wheelchairs or car adaptations to confer such individuals with independence in relation to their mobility or autonomy, as appropriate. Future research could also further examine the full range of values and meanings that prostheses can afford individuals with LLA beyond restoration of functional capabilities, such as those described in the current study. This could underline the potential meaning and value that prosthesis use can provide, which
could usefully inform interventions to encourage and motivate individuals to persist with prosthetic rehabilitation. This study also uncovered some novel findings in the area of prosthesis embodiment; experiences of prosthesis alienation and the use of disembodying language towards prostheses following LLA. Research is required to further elucidate this set of experiences in order to understand the conditions that undermine prosthesis embodiment and contribute to prosthesis abandonment. Finally, the present findings suggest that rehabilitation professionals should seek to reinforce conditions that promote feelings of prosthesis embodiment among individuals with LLA in order to encourage sustained prosthetic use.

In conclusion, the current findings demonstrate that individuals with LLA perceive and experience ATs to have uses beyond enhancement of their immediate functional capabilities. Individuals with LLA attribute particular meanings and values to such technologies that may influence the degree to which they engage with them. Similarly, emphasizing the importance of prosthetic devices, wheelchairs or car adaptations for enhancing autonomy or mobility may help to promote the use of such devices in rehabilitation settings. In addition, prosthesis alienation may point towards conditions that undermine prosthesis embodiment and contribute to prosthesis abandonment. These findings demonstrate the importance of ascertaining individuals’ experiences and perceptions of ATs beyond their functional capabilities in order to enhance satisfaction and encourage uptake of ATs.

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