The lived experience of older adults' adjustment to amputation in the context of wheelchair use

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ABSTRACT

Amputation has a profound psychological impact on recipients. The experience of adjustment to lower limb amputation (LLA) by older adults who use wheelchairs was explored using Interpretative Phenomenological Analysis (IPA). Four men with lower limb amputations due to vascular disease who identified as wheelchair users were interviewed. Participants' experiences of adjustment to LLA are represented by two themes: "Being an Active Agent" and "Psychosocial Adjustment as an Iterative Process". Being an Active Agent included three elements: self-reflection, a sense of control over one's LLA and the belief one is able to take action in decision-making in daily life. The second theme 'Psychosocial Adjustment as an Iterative Process' described the ongoing nature of the participants' narratives of adjustment to LLA. This theme also encompassed participants' experiences of adjustment to LLA as firmly linked to management of previous life events. Participants' adjustment did not appear to be directly influenced by the mobility aid they used; rather, the mobility aid provided opportunities for adjustment to occur. Older adults' adjustment to LLA appears to be influenced by their perception of being an active agent in their adjustment process, particularly in relation to decision-making. Adjustment also appears to be a process which older adults continue to engage in after the amputation event. The findings of this study suggest practical strategies that clinicians can use with older adults undergoing amputation.

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INTRODUCTION

Amputation is an end stage treatment option for individuals with vascular disease suffering profound and unresolving infection, pain and consequent immobility. Those undergoing (even) lifesaving amputation are likely to have lasting psychological sequelae. Those who undergo amputation because of vascular disease tend to be older and more likely to have both pain and lower physical functioning before their amputation, compared to those undergoing traumatic amputation (Kratz et al., 2010). They may also have co-morbidities such as diabetes (Peters et al., 2001), pain and obesity (Roberts et al., 2006), cardiovascular disease (Priebe, Davidoff, & Lampman, 1991), peripheral neuropathy (Potter, Maryniak, Yaworski, & Jones, 1998), reduced cognitive ability (Hanspal & Fisher, 1997) and phantom pain after amputation (Nikolajsen, Ilkjær, Krøner, Christensen, & Jensen, 1997). Within this population, wheelchair users tend to be older, have more co-morbidities, report higher levels of pain and fatigue and ambulate less efficiently (Karmarkar et al., 2009) compared to prosthesis users. Therefore it seems likely that wheelchair users may experience psychosocial adjustment to LLA in a different way to prosthesis users given their more complex health and personal profiles.

While adjustment in the context of prosthesis use post amputation has been well documented (Atherton & Robertson, 2006; Desmond, Gallagher, Henderson-Slater, & Chatfield, 2008; Murray & Forshaw, 2013), wheelchair use after amputation comes with its own set of less-reported challenges. In one qualitative study (Stokes et al., 2009) of 25 people with LLA (disease or trauma) who had returned home prior to prosthesis fitting, participants generally thought their wheelchairs were essential to them but at the same time viewed them negatively. Some participants reported that they felt "stuck" and like they were "second class citizens". Prolonged sitting and limited space to move were common challenges. While these perspectives draw attention to the difficulties faced by people who use a wheelchair before prosthesis fitting, the experience of those who use wheelchairs in the long term remains unclear; in particular, the process of adjustment to wheelchair use when this is likely to be long-term.

Various definitions of adjustment in the context of chronic health conditions exist, usually based around the presence of negative mental health outcomes such as depression and anxiety. Negative adjustment, or maladjustment, is when an individual suffers from overwhelming levels of grief, depression, anxiety or social discomfort, negative views of self or a lack of hope for the future or a change in circumstances (Gallagher & MacLachlan, 2000; Horgan & MacLachlan, 2004). Conversely, positive adjustment is described when:

> *The person places value on existing abilities and moves beyond physical losses (Wright, 1983), experiences an optimal level of congruence between the subjective world and the external environment (Shontz, 1975), and exhibits success in utilising problem-solving skills and in managing his or her environment (Roessler & Bolton, 1978).* (Smedema, Bakken-Gillen, & Dalton, 2009, p.51).

Psychological adjustment to acquired disability has also been conceptualised as a staged process in which an individual moves through a generally linear series of discrete stages (Smedema et al., 2009).

Several psychosocial variables have been shown to have a positive effect on adjustment to LLA. In prosthesis users, hope (Unwin, Kacperek, & Clarke, 2009) along with personal traits such as optimism and perceived control (Dunn, 1996; Oaksford, Frude, & Cuddihy, 2005) have been shown to be related to positive adjustment. While such studies have explored adjustment in the early years following amputation, some researchers (Hanley et al., 2004) have postulated that psychosocial variables may take a year or more to manifest fully in an individual's adjustment experience. Currently little is known about the experience of older adults who have undergone amputations and are living as wheelchair users despite their high risk for negative adjustment. The research question was: What is the experience of older adults' adjustment to lower limb amputation in the context of long-term wheelchair use?

METHODS

Design

This study was undertaken by LL, under supervision, as part of a Master's degree. Salient points regarding methodology and analysis are presented here for clarity. Interpretative Phenomenological Analysis (IPA) was chosen because it offers an in-depth understanding of the experiences of a small number of participants through idiographic, inductive and interrogative methods of analysis (Smith, Flowers, & Larkin, 2009).

This study took place in an urban centre in the South Island of New Zealand between 2011 and 2013. Ethical approval was provided by the regional Ethics Committee (URB/11/EXP/0390).

Participants

Participants aged over 65 years were identified from a publicly funded health database. Inclusion criteria were: lower limb amputation (vascular disease), amputation three or more years prior to the study (to allow substantial time for adjustment to have taken place); daily wheelchair user within the home; English language speaker and cognitive skills to participate in an interview (determined by their General Practitioner). Participants known to the interviewer (LL), a physiotherapist, were excluded. See Figure 1 for flow of participants in study. Four participants were interviewed for this study. See Table 1 for description of participants' characteristics.

Table 1: Participants' characteristics

Participants			Characteristics		
(pseudonym)	Age (year)	Amputation (level/ years prior to study)	Mobility Aids	Abode	Social Factors
George	75	Unilateral transtibial/5	Self-propelling wheelchair. Practising prosthetic walking with physiotherapist	Own home with carer visits and modification e.g. ramps	Widower, lived alone. Daughter nearby.
Barry	84	Unilateral transtibial/12	Self-propelling wheelchair for home based activities. Prosthetic leg for community use. Drove modified car.	Own home with modification e.g. ramps	Lived alone. Supportive neighbours.
Steve	90	Bilateral transfemoral/5	Powered wheelchair. Attendant propelled wheelchair as a back up	Own home with carer visiting twice daily and house modified e.g. ramps	Lived with his wife. Family nearby.
Tony	88	Unilateral transtibial/3	Attendant propelled wheelchair	Residential care facility	Some cognitive difficulty observed. English was his second language.

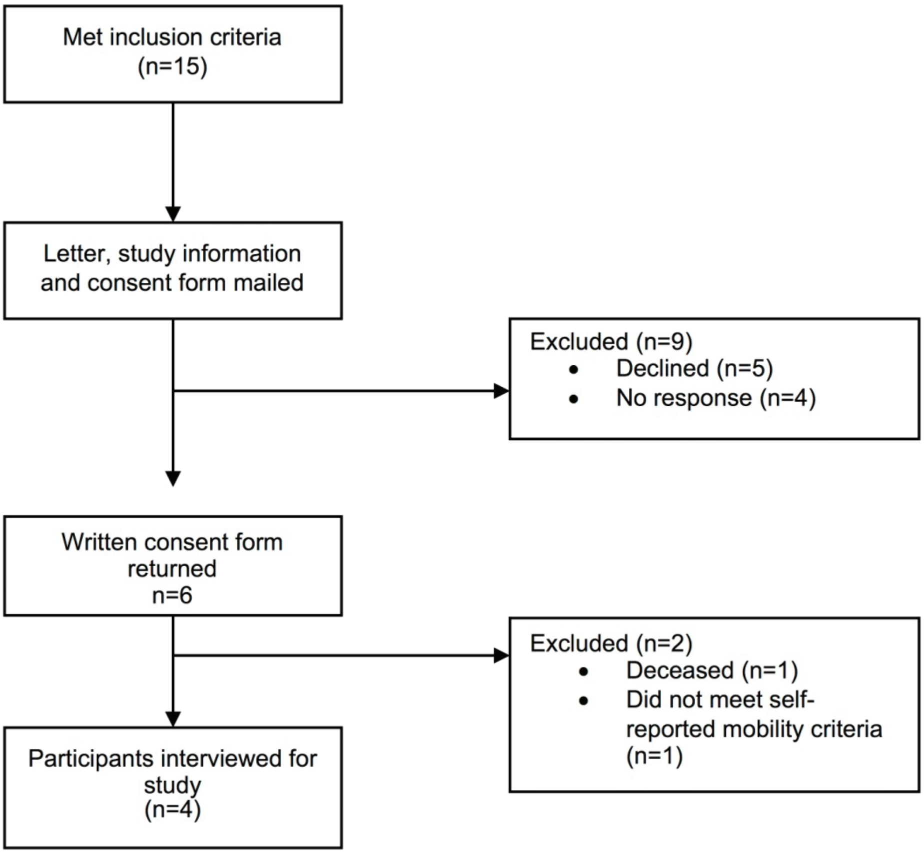

Figure 1: Flow of participants through study

Data Collection

Semi-structured interviews with an interview guide were conducted by LL in the participants' homes. One participant's wife was present and her comments were transcribed to add to the context of the participant's responses. Interviews lasted between 15 and 41 minutes. One interview was stopped at 15 minutes as the participant appeared to have some cognitive difficulty. Participants were encouraged to speak freely about their amputation experience and describe their current daily life. Interviews were audio-recorded and transcribed verbatim.

Consistent with IPA, LL made brief notes on the interview immediately after each interview including any comments that the participant had made after recording ceased. The interviewer also noted any initial reflections on themes and her own reactions that she had become aware of during the course of the interview. These notes formed a summary for each participant's interview and were referred to in the development of themes.

Data analysis

The primary researcher (LL) read through each transcript several times and made notes to become more familiar with their content. Dominant and recurrent expressions or ideas related to adjustment were highlighted. Notes were consolidated into a list of codes for each transcript with coding of a full transcript completed before moving to the next transcript. The four lists of codes (one for each of the four transcripts) were then compared with one another. Related codes from across the transcripts were then grouped together into preliminary themes, which were discussed by two of the authors (LL and FG) to clarify theme definitions and 'boundaries', and cross-check with coded data. Themes were then discussed by three of the authors (FG, LL and EJCHS) and refined further until a final set of themes was agreed.

Rigour

Rigour was sought using three strategies. First, methods of data collection and analysis were clearly documented. Second, all themes were discussed by multiple researchers (LL, FG and EJCHS). Third, all participants were invited to participate in member checking (Bradbury-Jones, Irvine, & Sambrook, 2010) via comment on a written or verbal summary of themes. Two participants responded to this invitation and agreed with the content of the summaries.

RESULTS

All four participants were men with an average age of 84 years. Only one participant lived with a spouse. See Table 1 for descriptions of the four participants: George, Barry, Steve and Tony. These descriptions give context to the participants' stories presented here.

Themes

Two main themes described the experience of older wheelchair users adjusting to LLA: (1) Being an Active Agent and (2) Adjustment is an Iterative Process (see Table Two). The first theme, "Being an Active Agent" highlighted three elements of adjustment: self-reflection, a sense of having control over one's situation and the belief one is able to take action in tasks like decision-making and daily life. The second theme, "Adjustment is Iterative" reflected how key experiences in the participants' adjustment to amputation were a part of an ongoing, cyclical pattern of adjusting to loss and change throughout life. Participants did not directly refer to how their wheelchair use influenced their adjustment to LLA. Instead, analysis showed wheelchair use was an integral part of how participants perceived a sense of agency (i.e. control) or not, in life following LLA and how they engaged in valued life activities.

Table 2: Results: Themes arising from Participants' narratives

Themes	Elements
Being an Active Agent	Self-reflection A sense of control Able to take action
Adjustment is Iterative	(nil)

Being an Active Agent

The theme reflected the overarching sense that participants' adjustment to LLA was impacted by the extent they were active agents in the events leading to and following their LLA. The three elements evident in this theme appeared linked by the importance of the participants as authors, or not, of their adjustment.

Self-reflection

Self-reflection appeared to facilitate participants' self-perception as active agents and help them plan a way forward. Barry's comments revealed the reflection he engaged in as he considered his life after amputation.

> *And I think it's in your mind, that you're gonna do it, you know, you could lie back and say, ohh poor me, couldn't ya'? You know, oh if it's me like, could say right ... I never took that attitude, I always thougth, ohh, I'll just get up and do it, you know. Mmm... I made it up from the start, it was ah, once I could get moving I's ... I've always been fairly active, you know, … [laughs] and so I thought, well I'm not going to miss out on that, I'm gonna get back, and get moving again. So ... I belong to, clubs and different things and ... I mean you get to the corner [point of decision] and say, poor me, and sit there but, but I thought oh I'm not gonna do that.*

Barry assessed his ability to adjust to amputation, the personal strengths he could draw on to help him adjust for example, his physical fitness and to explore his motivation to adjust to LLA through connecting with people at social clubs. Barry's narrative also illustrated the importance of his proactive attitude to adjustment. For Barry, adjusting to LLA could go one of two ways: being stuck in a "corner" and feeling sorry for himself or "get up" and strive to move and socialise again.

A sense of control over LLA

Three participants described times where they felt in control of the decisions leading up to and at the time of amputation, which appeared to have a powerful impact on their comfort several years later about the decision to amputate. George's description of the decision to amputate illustrated this:

> *The pain was really intense. So I went to my doctor … Mr [surgeon] said, we've got two options ... the knife ... or, some very strong painkillers ... I opted, as I would, for the strong painkillers. I lasted a day and a half. And I said to my doctor, 'for God's sake, put me into hospital' ... and he, Mr [surgeon] came 'round and he said, 'I knew you'd be back' ... so it's a loss ... but I have adapted to it.*

George's description of how he chose amputation from the treatment options offered him for his leg pain highlighted his sense of control in a seemingly inevitable situation. In contrast, Tony's narrative reflected a lack of control regarding amputation and his subsequent feelings.

> *…the nurse told me we have to amputate your leg ... and I was not so very happy about it ... they think it was really necessary to get it out of order ... I had, taken that in advance ... because I couldn't go on.*

Tony's comments appeared passive and disempowered. Tony's narrative lacked the sense of control over his health as expressed by the other participants. Instead, from Tony's perspective, control appeared to lie with health professionals, whom he perceived to have made the decision to amputate for him.

Able to take action

Although Steve was dependent on his carers and his powered wheelchair to move independently, he talked with satisfaction of what tasks he could do around his home.

> *... this one* [powered wheelchair] *I'm more independent. See you can, alter your position during the day … yeah about 12 hours on the bed and 12 hours on this, and that's me day!* [laughs] *... but at least you can move about ... I can go to the gate and get the mail and all that stuff … it's no hassle, ... I've got enough kindling wood cut for this winter … things are just going A1.*

Despite noting his day is spent in his bed or his wheelchair, Steve emphasised the actions he could do rather than his activity restrictions when he said: "at least you [meaning himself using his wheelchair] can move about". For Steve, being able to take action in his everyday life was important, not that this required wheelchair assisted mobility.

In contrast, Tony's sense of being able to take action in his life with LLA appeared to be less certain. Tony appeared troubled about the difficulty he had in everyday living with one leg and felt unable to cope.

> *I've got one leg ... I can't cope with one leg, really ... Well ... it's very hard to describe sometimes. I like to explain to the people how, how strongly I feel having one leg, you know? ... it's not very nice having one leg, and ah try to cope with it all, but I can't do it … I talked to my doctor ... but ... I was not very happy. Well he realized that. 'Specially on one leg, you know? And as I say, it's really hard … to follow the one leg system ...*

Like the other participants, Tony showed signs of attempting to find a solution or help from others when he spoke with his doctor. Ultimately though, his attempts were unsuccessful and Tony's comments portrayed his unhappiness in his struggle to "move on" or adjust to his LLA which he did not want. As a result, Tony appeared to be dealing with strong feelings of unhappiness and disempowerment.

Adjustment is an Iterative Process

Participants described their adjustment to LLA in the context of their current, previous and anticipated future experiences. This created a complex narrative that did not necessarily follow a chronological order nor have an 'end'. Rather, participants noted similarities and repetitions in their adjustment to a range of life events such as other losses or ill health. For example, George clearly described himself as having "adapted" to his leg amputation. Alongside this comment however ran a theme of repeated, painful loss (his wife, jobs, his ability to dance) which he hinted he was still dealing with when he described his daily anti-depressant: "… with this happy pill that I get, I have no feelings of loss". George described himself as having adjusted to his circumstances, yet feelings of loss clearly remained.

In contrast, Tony's narrative also featured iterations of disempowerment around his amputation which appeared to echo previous life events. Tony appeared to cycle between acknowledging amputation was needed for his health and not wanting his leg to be amputated.

> *I didn't want my leg amputated, because ah I want to keep it as long as I can … and I still can't understand why I have to wait so long* [for a doctor or answers] *… I'm waiting for a doctor … I've seen a doctor four times, I think. Four times … she ask me if I want to ah stay in here* [care facility]*, or go home.*

Tony's rumination acknowledged the "good" outcome of LLA, i.e. less pain from a deteriorating leg wound, and the not wanting LLA in the first place. Tony's amputation experience echoed another life experience of immigrating with family to "a very nice country" yet also wanting to return to his homeland. Tony referred to immigrating throughout his interview, although he did not directly connect this to amputation. However, the two narratives mirrored each other in that he could see the constructive aspects of both events while also feeling sad or discouraged when he reflected on them.

Steve's narrative also illustrated a cycle of adjustment to LLA as he both described progress he had made since having his amputation and acknowledged future ambitions.

> *I knew I'd get through it ... yeah ... there's a long way to go yet ... You got to live to 102 to break even with the government for your taxes ... It was in the* [newspaper] *years ago, I cut it out ... it said that the average person's got to live to 102. I said, well that'll do me. And that's my aim, yeah ... it's not going to be hard to do if I ... the way I am.*

Steve found a meaningful goal after LLA in aiming to live a long life and LLA was an intervention that helped him to achieve this goal. Despite recognising the LLA as valuable, Steve also acknowledged that it affected what he could do and how he lived. Negotiating this balance of value and difficulty was something Steve would be adjusting to for the rest of his life.

In contrast to Steve's goal-focused approach to adjustment, Barry centred on his adjustment to his identity. At the end of his interview he made the comment that he felt "I'm like an amputee, but not an amputee, you know?" Although having a leg physically amputated qualified him to label himself an amputee, he did not seem to feel this fully encapsulated how he saw himself because he was also "quite independent really", could "drive anywhere" (in his modified car) and "do what I like sort of thing". Barry's independence appeared at odds with how he perceived an amputee should look or behave.

DISCUSSION

Three of the participants' narratives reflected positive long-term psychosocial adjustment to LLA in the context of wheelchair use, with the fourth participant's comments reflecting negative adjustment. The narratives of the three participants with positive psychosocial adjustment (George, Barry and Steve) were consistent with findings relating to positive adjustment in chronic health conditions (Smedema et al., 2009), and in the broader literature on resilience through the lifespan (Windle, 2011). Resilience represents optimal adjustment, defined as 'the successful adaptation to adversity' (Zautra, Hall, & Murray, 2010) and includes a range of traits and coping qualities (Skodol, 2010) which align well with the themes identified in the current study.

The first main theme - being an "Active Agent" – appears linked to positive long-term adaptation to LLA. This is understood more clearly when the sub-elements of this theme are considered in relation to research on positive adjustment and resilience. First, the benefits of "Self-Reflection" in allowing a process of identifying strengths, finding motivation, and developing plans, is consistent with research findings that self-understanding contributes to resilience through such processes as (a) enabling the development of strong personal identities and a sense of purpose (Alim et al., 2008), and (b) facilitating enhanced regulation of strong emotions (Gross & Munoz, 1995). Self-reflection as described by participants in this study is also consistent with a large body of research linking positive psychosocial outcomes in people with chronic illness and disability with problem-focused coping styles (Chronister, Johnson, & Lind, 2009).

The second Active Agent sub-theme involved participants having a sense of control over their situations. This suggests they possessed self-efficacy, the belief that they could use their abilities to accomplish their goals, which is also consistently linked to positive coping (Bandura, 1997). The contrast between George (who appeared to view himself as having agency and choices) and Tony (whose passivity seemed marked) illustrated the significance of self-efficacy in successful rehabilitation (Marks, Allegrante, & Lorig, 2005). Related psychological constructs also relevant to this sub-theme include having an internal locus of control (Lefcourt, 1976), optimism (Seligman, 2006) and a sense of hope (Rand & Cheavens, 2009), all of which have been shown to be associated with resilient outcomes across a range of populations (Skodol, 2010). Having a sense of *control* is also a key component (one of the 'three Cs') of 'hardiness'. Hardiness includes having a *commitment* to a purposeful life, and accepting the *challenge* that life's inevitable changes bring (Kobasa, 1979).

The third sub-element of the Active Agent theme comprised participants' belief that they could take action around decision making in their lives. Like other elements of the Active Agent theme, this finding is also consistent with an apparent self-efficacy, indications of hardiness, and a problem-solving coping style in the three participants who described positive adjustment.

The second broad theme identified in participants' narratives was the experience of "Adjustment as an Iterative Process" involving an ongoing pattern of adaptation and coping with loss and change throughout life. This theme also aligns with the *challenge* facet of hardiness (i.e., accepting the challenge of change in life). Additionally, this finding is consistent with research associating resilience with a positive future orientation (Skodol, 2010), which involves a degree of optimism tempered by an acceptance of the need to be flexible and make adjustments to stressors that might arise in life (Southwick, Vythilingam, & Charney, 2005).

The main limitation of this study is the small sample size which reflects the challenges in researching the population of older adults living with an amputation. Combined with qualitative methodology, the generalisability of these findings to older adults with amputation as a whole is reduced. However, both the common themes and diversity of experience in this study indicate that further qualitative research with a larger sample size may yield a more detailed understanding of the process of adjustment to wheelchair use after LLA. Such research could further inform larger scale quantitative research using robust psychometric measures to examine the relationship between positive adjustment and the psychological indicators of resilient coping in older persons with LLA. Future research could also control for demographic and clinical factors such as gender (only male participants in this study), muscle strength, balance and cardiovascular fitness (mentioned by this study's participants). Research investigating variables associated with positive health outcomes which participants alluded to in the current study is warranted. For example, levels of social support (Taylor, 2011), personality and cognitive functioning (Deary, Weiss, & Batty, 2010).

With regard to clinical implications for physiotherapy, the current study reinforces current best practice (Broomhead et al., 2012) and provides grounds for integrating positive psychology within a strengths-focused rehabilitation approach to amputation (Elliot, Kurylo, & Rivera, 2002). The participants' experiences in this study suggest that the 'how' of mobility (prosthesis versus wheelchair) was not as important to them as the 'why'. Physiotherapists are well-placed to guide their client through the practical issues of mobilising (via walking or wheelchair) after amputation which in turn could influence the client's adjustment experience by focusing mobility rehabilitation at a client's participation in activities meaningful to the client and building their sense of self-efficacy, and through this their resilience and quality of life. Psychosocial elements of rehabilitation programmes incorporating positive psychology principles would include a focus on increasing positive effect, developing helpful traits and coping approaches, enhancing wellbeing, focusing on strengths, and taking a "person first" collaborative approach to care (Dunn & Brody, 2008; Dunn, Uswatte, & Elliot, 2009). Practical examples of these elements for physiotherapists include listening to clients' experiences during therapy sessions, using optimistic and encouraging communication, using client centred goals to direct therapy sessions (e.g., improving wheelchair mobility in the community to participate in social gatherings and hobbies). Although outside the scope of physiotherapy, physiotherapists must stay mindful of their client's mental health and be ready to refer on to appropriate mental health services, particularly in community-based therapy sessions where clients may feel more vulnerable or unsupported. It may also be helpful for physiotherapists to familiarise themselves with evidence-based general wellbeing practices, such as the New Zealand Mental Health Foundation's "Five Ways to Wellbeing" (Mental Health Foundation of New Zealand, 2015) with a view to reinforcing these with their clients.

CONCLUSION

This study, while restricted to a small sample of older men, identified important psychosocial factors associated with adjustment to LLA in long-term wheelchair users. These factors fell under two key themes: the benefits of being an active agent; and the iterative nature of adjustment. These themes, and their sub elements, align well with constructs found in the literature to be associated with positive outcomes in chronic health conditions, including self-efficacy, problem focused coping and a positive future orientation. Moreover, they point to the importance of physiotherapists who, understandably, focus on physical aspects of LLA rehabilitation, being mindful of their client's psychosocial functioning, reinforcing healthy coping and wellbeing strategies, and taking opportunities to refer on for mental health input where indicated.

KEY POINTS

1. A sense of agency (i.e. control) appears linked with wheelchair users' positive adjustment to lower limb amputation (LLA) which was demonstrated by self-reflection, perceiving a sense of control over one's LLA and that one is able to take action.
2. Adjustment to lower limb amputation was an iterative process situated within the context of the person's life.
3. During rehabilitation, physiotherapists can use positive psychology strategies to enhance their clients' adjustment to physical disability associated with LLA e.g. building resilience by focusing on a person's strengths and healthy approaches to coping.

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