Abstract

Purpose: To explore the expectations of patients about to undergo prosthetic rehabilitation following a lower limb amputation.

Method: Design: Qualitative study using semi-structured interviews.

Setting: Interviews were conducted at two district general hospitals.

Participants: Eight patients who had undergone a major lower limb amputation due to vascular insufficiency were interviewed within two weeks of their amputation. All patients had been referred for prosthetic rehabilitation.

Results: Five key themes emerged from the interviews: uncertainty, expectations in relation to the rehabilitation service, personal challenges, the prosthesis and returning to normality. These findings illustrate how participants faced uncertainty both pre- and postoperatively and often looked towards established amputees for the provision of accurate information.

Conclusions: As no previous research has specifically explored patients’ expectations following an amputation, this study adds valuable insight into the patient experience. Patient expectations following lower limb amputation appeared to be vague and uninformed which may lead to uncertainty and passivity. It was found that patients did not know what to expect in relation to the rehabilitation process. They expected to return to a normal life following an amputation and this expectation appeared to be an important coping mechanism. Patient information and discussions should form an important part of the rehabilitation process before as well as during prosthetic rehabilitation, to help shape realistic expectations. This will allow patients to take a more active, informed role in the process. Psychoeducation interventions (talking) appears to be as important as “walking” within prosthetic rehabilitation services.

Implications for Rehabilitation

• Patients’ expectations following lower limb amputation need to be informed by the rehabilitation team and established amputees from an early stage as part of the short- and long-term process of adjustment following amputation.

• Patient expectations of a return to normality appear to be an important part of coping following lower limb amputation, exploration of a new normal, both physically and psychosocially should be addressed as part of the rehabilitation process.
Introduction

Lower limb amputation is a traumatic and life changing event affecting many aspects of an individual’s life. Following an amputation, individuals normally begin an adjustment process where they adapt to both the physical and psychosocial challenges that arise throughout the rehabilitation process [1]. Many studies have focused on the physical factors affecting adjustment and the rehabilitation process, such as the individuals age [2–4], level of amputation [5,6] and the presence of comorbidities [7]. However, with regard to the psychosocial factors, the process of adjusting to amputation has been shown to be complex and there appears to be a wide spectrum of responses documented within the literature, such as anxiety and stress, depression, body-image anxiety, coping and phantom limb sensations including pain [8–13]. In terms of positive adjustment, qualitative work carried out by Murray [14] found that amputees felt that adapting to a prosthesis was an on-going activity and initial problems became more manageable over time as prosthetic use became more natural and required less concentration. It was suggested that rejection of the prosthetic limb may occur if the participants could not get over the problems and adjust to wearing the prosthesis. These finding have been supported in a recent qualitative metasynthesis where several studies have described emotional ambiguity in the early stages following amputation where patients deal with the loss of their limb in the light of a future of prosthetic limb use [15]. In addition to factors related to successful prosthetic use, the qualitative metasynthesis results highlighted the importance of social considerations, such as social acceptance in terms of experiencing a positive attitude from family and friends, the importance of social comparison and positive social interactions. From this it has been suggested that, prior to and immediately following amputation, the rehabilitation team should provide patients with education and psychological support (termed as “psychoeducational interventions”) about what should be expected in order to prepare them for what will happen. This could go some way to addressing these commonly experienced issues shown in the qualitative research.

The importance of education has also been shown in a focus group study carried out by Gallagher and McLaughlan [16] aiming to identify factors that amputees felt were important in the adjustment process. Education was seen as a key part of adjustment with patients often describing how they wanted to know what their prosthesis would look like and how it would function within their own lives. It was found that patients often benefited from contact with established amputees as they were seen as a valuable source of information, based on personal experience, which provided a form of positive modelling for amputees as well as helping to promote the change process [16]. It was suggested that patients may cope better with the amputation process if they know what to expect rather than fearing the unknown, illustrating the importance of patient expectations.

Although a growing body of research has illustrated the importance of psychosocial support and education in facilitating the adjustment process following an amputation, there appears to be little research looking specifically at patient expectations. However, in other areas of rehabilitation, such as research within the field of stroke rehabilitation, it has shown that expectations can have an impact on the way that patients adjust to a new disability [17,18]. Other studies investigating expectations following orthopaedic surgery have found that positive expectations can increase a patient’s motivation and adherence to treatment recommendations [19]. It is thought that high expectations may serve as a coping mechanism for patients, helping them to accept their treatment and time in hospital [20].
However, if expectations are not met, it has been found that patients may feel dissatisfied with the services provided and this can lead to an increase in stress levels [20]. This may affect adherence, motivation and subsequently the overall success of the rehabilitation process.

Previous research within the area of amputation has started to develop a good understanding of the experience of amputation and prosthesis use for adults, which has important implications for the delivery of rehabilitation services [15]. However, no previous research has specifically explored the expectations of patients who have had an amputation and would be taking part in prosthetic rehabilitation. Exploring and understanding the expectations of these patients may provide further insight into the patient experience and can help inform health care professionals of specific factors that may help support patients through this process strengthening the current body of research. Therefore, the aim of this study was to address the following research question: What are the expectations of patients immediately after undergoing lower limb amputation regarding the prosthetic limb, the rehabilitation process and the outcome of rehabilitation?

Method

A qualitative approach to answering the research question was taken, which involved data gathering via semi-structured interviews. Participants were recruited from two district general hospitals in the South of England. They were invited to participate if they were (i) over 18 years old, (ii) had undergone a major lower limb amputation within the past two weeks, (iii) only just started the rehabilitation process and (iv) been referred for prosthetic rehabilitation. This was to explore patients’ expectations prior to their exposure to prosthetic rehabilitation and prosthetic limbs. Participants undergoing a second amputation were excluded, as they would have prior knowledge and expectations of the rehabilitation process. Due to time constraints, a convenience sampling method was employed to recruit the participants. Ethics and R&D approval was gained from the Local NHS Research Ethics Committee.

The recruitment process involved identifying a clinician at each hospital to act as the main gate keeper. Each clinician identified patients who fulfilled the inclusion criteria and gave them a study information pack containing an invitation letter, participant information sheet and a reply slip. Patients who were interested in taking part in the study were contacted within two weeks of their amputation. A convenient time was arranged for the interviews and consent was taken face to face at the start of each interview.

Interviews

The interviews were carried out by the first author in the hospital as, at this point, the participants were in-patients. A quiet room was used to minimise the chance of disruptions to the interview and to help the participants feel relaxed. All participants agreed and consented to the interviews being audiotaped. The interview guide included demographic questions, such as age, cause of amputation, medical history and social situation. Participants were asked to discuss their expectations of the rehabilitation process, such as how long they thought it would take, who they thought would be involved, what the likely process would involve and when certain issues would occur during this process. Participants were also asked what they thought about the type of prosthetic limb they may receive, with questions
focussing on aesthetic expectations, comfort, usage and acceptance of the limb. Finally, participants were asked about their expectations of life with a prosthetic limb, regarding issues such as their independence with their hobbies or activities of daily living and their overall adjustment to amputation. Interview questions were derived from the literature and from clinical experience.

Analysis

The interviews were transcribed verbatim. Thematic analysis [21] was used to develop codes and themes from the transcripts. Initially each participant’s transcript was read and re-read with initial ideas being noted. Codes were generated by noting interesting comments systematically across all of the transcripts; all relevant codes were then collated into potential themes. The first author undertook the analysis; however, a second researcher (the second author) analysed two of the transcripts to identify any alternative interpretations which could be included in the analysis. The potential themes were compared and contrasted across all of the participants. On-going analysis, incorporating negative cases was used to refine the final themes.

Results

Six men and two women were interviewed, following their lower limb amputation. Two underwent transfemoral (above knee) amputations and six underwent transtibial (below knee) amputations. Their ages ranged from 22 to 77 years (mean ¼ 51 years) and two of the patients lived with their families or partners. The cause of amputation for all of the patients was dysvascularity (Table 1).

Table 1 Participant demographics

<table>
<thead>
<tr>
<th>Centre</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Level of amputation</th>
<th>Cause of amputation</th>
<th>Social situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Molly*</td>
<td>A</td>
<td>Female</td>
<td>67</td>
<td>Transfemoral</td>
<td>PVD with diabetes</td>
</tr>
<tr>
<td>Graham</td>
<td>A</td>
<td>Male</td>
<td>46</td>
<td>Transfemoral</td>
<td>PVD</td>
</tr>
<tr>
<td>Tom</td>
<td>A</td>
<td>Male</td>
<td>61</td>
<td>Transtibial</td>
<td>PVD</td>
</tr>
<tr>
<td>George</td>
<td>B</td>
<td>Male</td>
<td>77</td>
<td>Transtibial</td>
<td>PVD</td>
</tr>
<tr>
<td>Diana</td>
<td>A</td>
<td>Female</td>
<td>41</td>
<td>Transtibial</td>
<td>Diabetes</td>
</tr>
<tr>
<td>Trevor</td>
<td>B</td>
<td>Male</td>
<td>60</td>
<td>Transtibial</td>
<td>PVD with diabetes</td>
</tr>
<tr>
<td>Charlie</td>
<td>A</td>
<td>Male</td>
<td>22</td>
<td>Transtibial</td>
<td>Insect bite</td>
</tr>
<tr>
<td>Derek</td>
<td>B</td>
<td>Male</td>
<td>33</td>
<td>Transtibial</td>
<td>Ulcers</td>
</tr>
</tbody>
</table>

*Pseudonyms are used throughout.

Data analysis identified five key themes relating to

- “Uncertainty” from the past and now for the future
- “I don’t know what to expect, so tell me what to do”
• Personal challenges ahead
• “Replacing the leg I lost”
• Returning to normality

Each theme is discussed below and supported with direct quotes from the participants, using pseudonyms throughout.

“Uncertainty” from the past and now for the future

Uncertainty was a key theme running throughout most of the participants’ discussions and which appeared to have been part of participants’ lives for some time. In the first instance, uncertainty related to whether or not the participants would actually have to have an amputation. This was experienced pre-operatively by many of the participants. As Trevor said

I’ve lived with that (ulcer) for two years. I added up a few days ago ... and counting the, only the one leg that was really infected, I’ve had over 780 bandage changes and each one of those dressing changes, I’ve had the worry that erm that would be the one that they would say, nothing more we can do, the legs got to come off. (Trevor, lines 138–146)

Diana describes similar experiences

Yes cos I’ve been in quite a few times with the infection and he said kept saying you do realise that one day it is going to have to come off. (Diana, lines 18–21)

Uncertainty did not end with the decision to amputate and appeared to continue post-operatively. Participants were very unsure of what the final outcome would be following the amputation and how this outcome would impact their lives.

I would like to be independent, well, with my cooking. Well, with my house really to be independent there so I haven’t, I mean I suppose I’m always going to be a little bit reliant on somebody but hopefully not too much. I would like to think that I would get back to complete, but, I think I’ll have to wait and see on that one. (Molly, lines 553–561)

Participants expected to be able to overcome their uncertainty by talking to other amputees. Contact with other amputees was discussed by all of the participants in the study, being highlighted as an essential source of information about what “really” happens. As George explains:

I would mainly like to ask people who have got artificial limbs cause there’s little things that come in at the side that maybe the professionals aren’t aware of or don’t know about so I think they are the people. I mean the professionals are going to tell me what I should expect, but the amputees are going to tell me what I will, what I can expect, they’re going to be able to tell me exactly what happened what goes wrong, you know, if there are things that go wrong. (George, lines 666–679)

It appears that obtaining some degree of certainty about their status may help amputees establish realistic expectations concerning their situations, which would then allow them to feel more secure in the expectations they do have. Although in many cases it can be difficult to accurately predict physical outcomes, it may still be important to give as accurate as
possible information regarding the rehabilitation process as this is to reassure patients of their journey ahead.

“I don’t know what to expect, so tell me what to do”

The participants had varying knowledge about rehabilitation services, with some being more accurate than others. It was clear that little information about the process had been given to them at this stage and the participants’ expectations about the process they were about to undertake were fairly vague. It is interesting to note that many participants likened the process to going back to school.

I think it will be like going back to school, learning how to do it I suppose, learning how to do more (pause) with your new leg when you get it, it’s going to be hard I’m sure it’s going to be hard, there’ll probably be days when I think oh what am I doing here? (Molly, lines 207–214)

Rehabilitation was often described in a very passive way with someone else directing it and telling the participants what was required of them.

Basically just doing it, if they set tasks for me to do, just basically making sure that I do them really, if I’m told not to do something, make sure I don’t do it. (Diana, lines 143–146) Just to do what I’m told, (laughs) that’s all I can expect. (Graham, lines 250–251)

These participants described rehabilitation as a service in which they had little control over what they were going to be doing. However, this expectation that rehabilitation would be like “school” or a paternal environment was not described in a negative way and the participants did not appear to have a negative view of this expectation.

Participants were not always clear about the health care professions they thought would be involved in the rehabilitation process. All participants mentioned the physiotherapist and some mentioned occupational therapists. Although all participants mentioned the involvement of doctors and nurses, participants seemed unclear about their actual role in the rehabilitation process. A key member of the rehabilitation team, who was not mentioned by any of the participants, was the prosthetist. This is interesting as, due to the prosthetic adjustments and the possible need for new prosthetics, it is often found that the prosthetist is the team member who will remain in the patient’s life after other therapies have finished. There was no expectation from any of the participants as to who would make the limb or maintain it, especially in the long term.

Personal challenges ahead

All of the participants expected that the process they were embarking on would be hard physical work.

I got to think I’ve got to go down there, got to get it done, you know, get my leg, and just keep fighting forward. Not to give in ... I’m not going to just sort of go there, thinking that it’s going to be easy, it’s not, it’s going to be hard work I think first, (pause) hopefully not too hard (laughs). (Molly, lines 371–374)

If you’ve got to do it you’ve got to do it. It’s one of the things to allow you to lead a normal life otherwise you’ll end up stuck in a wheelchair for the rest of your life. well I don’t
want to be stuck in a wheelchair for the rest of my life. I’m determined to walk, whether I can or not that’s a different story only time will tell. (Tom, lines 230–238)

Most participants discussed how they would need to try and contain or address the psychological and social challenges they would face throughout the rehabilitation process. Participants discussed how a positive, determined attitude was felt to be very important to ensure a successful outcome following rehabilitation, with several participants describing how they would “have” to be positive and that there would be consequences if they were not. This was expressed in humorous terms by Graham:

Well mentally the way is em I mean you’ve just got to look forward there’s no point sitting there and moping and saying no I can’t do this, you’ve got to have focus and say yes I can do this. And even if you do have a few setbacks, just take them and say oh well that’s another day tomorrow and start again. Cause if you don’t you’re not going to get anywhere. And if you just go into that sort of deep world depression, well it’s just it’s going to end up pointless isn’t it ... at the moment em just to make a sort of em joke of things to try and keep things up. Em I call my stump Mr Stumpy. (Graham, lines 398–411)

Several of the participants described the rehabilitation process as a fight to regain their independence; nevertheless, being able to retain their positive attitude was seen as just as important as their physical recovery and the consequences of negativity were perceived as dire.

my biggest advice to anybody would be to move heaven and earth to keep up the momentum or exercise and therapies of all sorts. Forget the mumbo jumbo side of it, concentrate on the physical side of it and simply don’t let it all lapse, don’t let it stop, Momentum is absolutely everything keeping going, keeping going fast, not really giving yourself time to think. (Trevor, lines 826–839)

“Replacing the leg I lost”

As would be expected the issue of how the prosthetic limb would look was important. The colour of the limb was expected to be brown or skin coloured.

I’ve tried to visualise that (the prosthesis), (pause) seeing people that have got them it’s just, it’s just brown isn’t it? (Molly, lines 265–267)

The degree of movement of the knee joint was also mentioned, as Graham says

Hopefully skin coloured and em hopefully a bendy one. Em, my partner has seen a couple of people walking round town in XXXX city centre their leg hasn’t got a bend in it, so their having to sway their hip to walk you know. (Graham, lines 512–519)

Most participants, including the two women, felt that the appearance of the limb was not important because it could be covered up by clothing.

It doesn’t really matter how it looks cause it will be covered up anyway. (Derek, lines 386–387)

How it looks is not really important because I wear jeans all the time so it doesn’t make a lot of difference, it’s only me that’s going to put it on in the morning and wear it under jeans
so nobody’s going to see it so it don’t ... so it doesn’t matter really. (Diana, lines 288–296)

However, the visibility of feet and the expectations of what footwear could be worn on the prosthetic foot appeared to be important issues.

I don’t really care because I’m going to have trousers on anyway, you’re not going to be able to see it em the shoe the shoe department comes in a bit here though. (George, lines 379–383)

I hope it looks nice, obviously you know if you want to go out you want to be able to (pause) look nice and, put a nice shoe on the the other foot. (Molly, lines 289–295)

**Returning to normality**

Despite several participants acknowledging that they were likely to have reduced function with a prosthesis, it was found that participants were still expecting to be able to return to many of the activities that they had carried out in the past. This contradiction in their viewpoints related to two subthemes relating to (a) “returning to normal” and (b) “not returning to normal”.

**Back to normality**

The key factor in the return to normality for all participants was the prosthesis, which was viewed as a replacement leg and would therefore let them do what they did in the past. This was echoed by Charlie who said

“with the prosthetic leg I’m normal again sort of thing” (Charlie, lines 548–549).

The issue of normality was important to all participants and was raised repeatedly throughout all of the interviews. Although participants often talked about wanting to walk again, this expectation of returning to normality went beyond just the taking of steps. Indeed, there was a desire to be able to negotiate uneven ground and unpredictable environments. For example, Tom said,

well I hope to go fishing out of the boat again, so just normal really sort of walk as far as I could before. (Tom, lines 355–357)

**Not back to normality**

Despite this aim to achieve normality, several participants appeared to be aware of the restrictions they may face when using a prosthesis, such as reduced exercise tolerance, difficult social situations and the impact on career choices.

I’ve looked at sort of thing like, I was going to become a plumber you know, I was looking at gas engineer, plumber, and I sort of thought picking up heavy objects and kneeling down sort of was a bit too much I think so em, so I opted for electrician. (Charlie, lines 728–735)

Diana said,

My friend has got a hot tub and she says oh you’ll have to come in the hot tub and I’m not going to be able to do anything really like that. (Diana, lines 468–472)
It was also felt that spontaneity and speed would be compromised.

"It'll be like I can't just em hang on lads I'm going to go for a quick shower and then I'll meet you cause I’d have to basically take my leg off, hop to the shower and you know I’m always going to have to have like shower aids, stuff like that you know. I’ll have to think about things, I can’t just do things out of the blue. (Charlie, lines 835–855)

In the past I've done like I'm doing a bit of gardening oh damn I've forgotten something, dash indoors, get it, dash outside, that, that I'm going to have to forfeit a bit. (George, lines 607–610)

Some participants’ discussion of the possible restrictions often seemed to contradict their expectations that they would be able to return to normal. This contradiction may be part of the process of coming to terms with the “new normal” they now had to face.

Discussion

The key findings of this research were related to five key themes:

“uncertainty from the past and now for the future”, “I don’t know what to expect, so tell me what to do”, “personal challenges ahead”, “replacing the leg I lost” and “returning to normality”.

The participants were facing great uncertainty following amputation of their lower limb. Uncertainty had existed pre-operatively and was again a major factor in the post-operative phase, as participants wondered about the rehabilitation process and how successful they would be at the end of it. A study by Gallagher and MacLachlan [22] found that amputees often described feelings of insecurity and apprehension in the early stages following amputation, and that the provision of physical and psychological support and information about the amputee rehabilitation process at this point was important in addressing these concerns. The results from this study suggest that participants expect established amputees to be their key informants. This is supported by a number of studies. Oaksford et al. [23] suggested that established amputees are seen as credible informants and that access to them should be a standard part of rehabilitation. Gallagher and MacLachlan [22] suggest amputees may act as positive role models helping patients who are new amputees, to believe they could achieve the same things.

In addition to encouraging patients to ask about their prosthesis and rehabilitation from an early stage after their amputation, the provision of accurate information will allow people to share their expectations and clarify issues for themselves. The participant’s expectations of the rehabilitation process were found to be vague in terms of the length of time their rehabilitation might take and how often they would need to take part, and they had clearly not received much information. However, they were all clear in their description of the rehabilitation process in a passive way, likening it to the school environment. This passivity was also described in a study by Murray [24] who found that when amputees lacked information or experience, in this case with prosthetic limb fitting, they became more passive and bowed to the “experts” when they felt they were unable to contribute to decision making, even in situations where they may have been encouraged to. Other studies report
that patients often adopt a passive role while they are in hospital and this may be due to the highly structured in-patient environment [25,26]. This passive expectation differs from the patient led health care service described by health care providers. Achieving this patient driven service may be dependent on health care providers adequately informing patients of what to expect. Within amputee rehabilitation, the use of pre-amputation consultations and meeting established amputees should be more of a priority even in cases where time is limited. However, it is important to consider that these passive expectations and the structured environment they sit within, may be an important part of coping for amputees during periods of great uncertainty and clinically should be recognised as such.

One area which was wholly unclear was the expectation of the role of the prosthetist. This lack of expectation may be reflected in a lack of research surrounding the role of the prosthetist and clinically this should be addressed so that patients can be prepared for this new partnership and understand the frame of reference for the role. It may be that a lack of recognition of the prosthetist’s role links to a lack of recognition that the prosthesis will need to be manufactured and will not be a fully functioning replacement limb, as hoped for by many participants. Murray [24] also found that even when the patient prosthetist relationship was more established amputees still did not know what to expect from the interaction with the prosthetist. This could lead to passivity, communications issues and subsequently disappointment and lack of engagement with services.

Participants also talked at length about the importance of maintaining a positive attitude throughout rehabilitation and suggested that if this positive attitude was not maintained there would be detrimental consequences. This determined attitude has been described in other studies; for example, Oaksford et al. [23] noted that patients needed to feel a sense of control over their situation and often dealt with the traumatic event of an amputation by trying to look towards the future in a positive way. The implications of not maintaining this attitude may be added to the adjustment concerns faced by the new amputee. This highlights the need to address these concerns and offer psychological support whereby amputees can gain a sense of control over the situation that is likely to be constantly changing.

The expectation of a return to normality was the main expectation in this study: the key to this normality was often described as being able to walk. This is consistent with research conducted by Gallagher and MacLachlan [22] who reported that patients initially focused on the importance of being able to walk. Once they were able to walk they then faced the practical difficulties of transferring the physical act of walking into the life they were previously living, i.e. to functional activities at home or leisure and vocational activities outdoors. The participants in this study did not always consider that being able to walk does not equate to normality. This was also discussed in a study by Murray [27] who reported that even when first wearing the prosthesis participants were able to get a sense of their own self-identity. This was not purely about mobility, which could be achieved in a wheelchair, but the prospect of normal walking. This gap in expectations between being able to walk and being normal could lead to problems with disappointment and subsequent dissatisfaction as the reality of prosthetic use becomes apparent.

Despite participants often describing that they expected to return to “normal”, they also described scenarios where they knew this would not be possible and would have to accept changes from their old life. Hamill et al. [28] and Senra et al. [29] both described the process of regaining a sense of normality in their qualitative analyses of experiences following
amputation. They described the process as a re-negotiation of self-identity. Their participants faced resistance within themselves to accept their new “disabled” identity and that this highly personal experience may involve a period of “reality negotiation” to fully adjust to the changes brought about by amputation. Carpenter [30] described this process as aligning the “internal self”, the same person the patient knew themselves to be, with the “external self”, the person with a new disability and altered body image. This process of alignment was found to be facilitated by time, the patient taking responsibility for their rehabilitation and the development of “a new framework of disability experience” Carpenter [30]. The contradictions described in this study, between what the participants expected to be able to do and what they can actually do, could be the beginnings of creating a new framework of disability experience or a “new normal”. However, this process can only be managed successfully if discussed with others and support is given to enable patients to respond creatively to their new situation, as well as to encourage them to keep trying to overcome the challenges they face. Oaksford et al. [23] suggest that, for amputees, actively aiming to solve the challenges they face is an important coping strategy and is often linked to positive adjustment. Discussing and realistically working through these contradictions as they arise throughout the rehabilitation process may help patients to develop this problem solving approach and aid the acceptance of their new normal.

A key challenge participants expected to face concerned how to manage their altered self-identity in social situations, where the amputation may become visible (i.e. on the beach, or during sports, etc.). This was also described by Murray [31] who reported that when a disability such as an amputation is highly visible amputees may withdraw from social situations as a way of managing their altered self-identity. This can be overcome by using the prosthesis to conceal the disability and allow the amputee to control when and to whom they disclose the information. Oaksford et al. [23] highlighted that patients can feel very socially isolated after an amputation and that even just one negative social interaction can have serious emotional and behavioural consequences. Supporting amputees through this process, in terms of addressing the actual and perceived social stigmas of their new disability, should also be considered as part of the rehabilitation process [10]. Murray [27] observed the concept of “self-display” among his study participants which was originally described by Frank (1998). This concept where the amputee actively chooses to make their disability more visible (such as young amputees rejecting cosmetic limb covers for a more bionic appearance) could be developed into strategies for managing the associated stigma.

When considering the findings of this study, it is necessary to put them into their specific context. This is not a national study and only included a relatively small number of participants from two limb centres. A total of eight amputees were involved and therefore the results do not necessarily represent a diverse range of views. Although the sample varied in age and gender, the cause of amputation for all of the participants was vascular insufficiency, which is not surprising when considering this is the main cause of amputation in the United Kingdom [32]. However, as this is the only cause of amputation considered in this study, these findings may not encompass the views of patients who lost their limb due to other causes, such as trauma or cancer.
Conclusion

Patient expectations following lower limb amputation appear to be vague and uninformed which may lead to uncertainty and passivity. It appears that patients’ expectations are formed during contact with other amputees and health care professionals or through information we have generated. Clinicians do not always consider the complexities of adjusting to lower limb amputation and often do not talk with patients about their expectations of recovery. Patient information and patient discussions are a vital part of the rehabilitation and adjustment process following lower limb amputation and should incorporate and inform patient expectations to aid the individual’s engagement in services for the future. It should also be recognised that high expectations may be an important part of psychosocial coping following amputation and that fully managing expectations may be a more long-term process. There is a real need for the physical and psychological rehabilitation teams to work together with patients to help inform and shape realistic expectations, through problem-solving approaches, as part of both the short- and the long-term process of adjustment to amputation. Time within the rehabilitation process should be dedicated to helping the individual to find “a new normal”. Perhaps the key message from this study is that, within amputee rehabilitation, “more time should be dedicated to talking, rather than just walking”.

References


