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Being a peer support mentor for individuals who have had a lower limb amputation: An interpretative phenomenological analysis

Abstract

Purpose: Although peer support has received research attention within different health related contexts, there is limited research considering individuals who have experienced an amputation. In particular, the peer mentoring role is under-explored. Therefore, this research aimed to explore the experiences of participants delivering peer support interventions to individuals with lower limb loss.

Methods: Eight people who acted as peer mentors for people with limb loss took part in semi-structured interviews. Data were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Two overarching themes were identified from the data: ‘Developing a Helpful Self’, in which the personal value and meaning of being a peer mentor is presented, and ‘Connecting with Vulnerability’, which addresses the emotional challenges of peer mentoring and the impact of these on well-being.

Conclusions: Findings suggest positive experiences of providing support, including increased hope, resilience and a sense of belonging and connection to others. However, peer mentors experienced challenges related to uncertainty and doubt about their mentoring abilities and with developing and maintaining resilience in the role. Recommendations include the development of training packages and increased clarity for volunteers of the peer mentor role.

Key words: Limb loss; qualitative; peer mentor; peer visitor; social support; volunteer

Being a peer support mentor for individuals who have had a lower limb amputation: An interpretative phenomenological analysis

An amputation can affect an individual physically and socially, potentially resulting in depression and other psychological difficulties [1]. Physical challenges include reduced mobility, chronic pain, skin breakdown and infection, and adjusting to the use of an artificial limb [2]. Individuals may avoid social contact due to the potential for stigma and negative reactions; this can negatively affect their perceived quality of life and their ability to develop and maintain relationships [3]. However, although some may experience long-term psychological difficulties [1], many individuals successfully adjust to their amputation over time [4].

Research suggests that accessing social support (whereby individuals, social networks or wider communities provide a person with practical, emotional or psychological resources that are experienced positively) may accelerate an individual's ability to adapt and cope with limb loss [5]. One type of social support employed within healthcare settings is peer support, involving a mutual and trusting relationship based on lived experience between two or more individuals facing similar circumstances [6]. It aims to promote behaviour change and improve self-care [7], and offer support, encouragement, hope and mentorship [8]. Although it contains aspects of therapeutic or educational support, the role relies on experiential knowledge rather than formal training [9]. Additionally, peer mentors are considered to be in a unique position to offer empathy and validation through experiencing similar circumstances to the person they are supporting [10].

There is limited research considering peer support for individuals with limb loss [11], despite suggestions that it may enhance recovery [3]. Several papers describe how peer support can be applied to individual or group settings for people with amputation [12-14]. Valizadeh et al. [5] reported that peer-interaction for people with limb loss can help them to problem-solve, provide information and facilitate positive emotions.

To date, although there is some literature examining the benefits of receiving peer support following limb loss, and peer support is recommended in the rehabilitation process [11], there is no literature examining the experience of delivering this peer support by mentors. However, findings from other studies suggest that delivering peer support can have a positive impact on wellbeing and adjustment to physical health conditions [15]. Peer mentors can experience a sense of purpose, empowerment, increased self-esteem, social acceptance, value and achievement through establishing relationships and connections with others [16]. However, challenges have also been identified within the literature, for example, negative emotions such as feelings of rejection, loss, failure, inadequacy, isolation, or emotional entanglement. This can affect mentors' own wellbeing through revisiting negative emotion related to their experiences [16-17].

Given the long-term consequences of amputation, it is important to examine the particular experiences of individuals undertaking peer mentoring roles in order to guide best practice for implementing peer support and appropriately supporting mentors in delivering such interventions. Therefore, the current research aims to address this gap in the literature by exploring the experiences of individuals delivering peer support.

Method

Design

This study received approval from the ethics committee of the employing University of the third author. Data were obtained via semi-structured interviews and were analysed using Interpretative Phenomenological Analysis (IPA). IPA is a qualitative approach to analysis founded on a blend of phenomenology, hermeneutics and idiography that is interested in an individual's detailed and subjective lived experience [18]. In practice, the approach looks to explore how participants experience their world through the analysis of data from small,

homogenous samples, acknowledging the active role of the researcher in the interpretation of these experiences.

Sampling and participants

The current research recruited participants from a national advocacy charity in the UK for people with limb loss. Peer mentors are members of this service who have experienced limb loss at least two years previously, and are asked by the charity to share their knowledge and experience of amputation. Peer mentors do not receive formal training, but are advised by the charity that they are different to medical professionals or counsellors, and are directed against providing medical, psychological, legal or financial advice. They can visit individuals at home or in hospital, or speak by telephone. The frequency of contact between mentors and mentees is negotiated between them on a one-to-one basis and there is, then, no typical characteristics of support in terms of number and timing of visits or contacts.

The sample pool consisted of thirty people volunteer peer mentors. Details regarding the study were provided directly to all mentors via the charity. Of the thirty volunteers, ten of these contacted the research team within the data collection period of the study (a further three people expressed an interest after data collection was complete). Although it is not known why others did not express an interest in taking part, the charity informed the authors that not all mentors had acted in a mentoring role at the time of recruitment and that some mentors performed the role infrequently. Of the ten mentors who expressed an interest in the study, two were excluded because they had not yet acted in a peer mentor role. Eight people (5 females, 3 males) took part in the study (this is in accordance with recommended sample sizes of 4-10 for IPA in order to facilitate an idiographic analysis). All participants had considerable experience of mentoring (2-15 years) and first-hand experience of amputation and prosthesis use (7-48 years) so are considered appropriate informants for the research aims

of the study. All were white British and used a prosthesis. Ages at interview ranged from 57-64. Demographic information is provided in Table 1.

[INSERT TABLE 1 ABOUT HERE]

Data collection

The advocacy charity sent out a study pack containing details of the study to peer mentors via post and email on behalf of the research team. The pack included a letter inviting participation in the study, a participant information sheet (explaining what the study was about and what participation involved, along with details of mental health charities who could offer support if needed), consent form, and the contact details of the researchers. The postal pack also contained a self-addressed envelope and ‘consent to contact’ form if potential participants preferred to provide their contact details and have the researcher contact them. Interested mentors made contact through telephone, email or by returning a consent to contact form. Participants signed and posted a consent form prior to their interview taking place and consent was also recorded during the interview. The limits of anonymity and confidentiality were outlined in the participant information sheet and participants provided signed consent for data excerpts and demographic information to be reported in any research outputs providing pseudonyms were used. All participants were interviewed by the first author over the telephone (average length 62 minutes), apart from one individual who lived locally and completed the interview at home. All interviews were audio-recorded and transcribed verbatim. Semi-structured interviews were completed based on the research questions and aims (see appendix A). Open-ended questions were asked, allowing participants to discuss experiences in detail; for example: ‘Can you tell me about your experiences of offering peer support?’; ‘What is your opinion of the peer support service?’; and ‘How would you like to see the peer support service develop in the future?’ When following up responses to

evaluative questions (such as the latter two), care was taken to direct participants to discuss how their responses were informed by their experiences and interpretation of events.

Data analysis

Smith et al's. [18] analysis process for IPA was followed. Analysis involved line-by-line coding of each transcript in isolation, focussing on the research question ('What are participants' experiences of providing peer support?'). In keeping with the idiographic philosophy of IPA, the entire text of each transcript was treated as a whole and coded thoroughly. Interpretative notes were made on the transcript in the left most column next to segments of text that were of interest in relation to the research aims/question. When coding was completed the interpretative notes were reviewed to identify patterns of meaning, or themes, that ran throughout the transcript in relation to the focus of research interest. Following the identification of initial themes, these were then reviewed to identify higher order, overarching themes. When this theme structure had been developed, the researcher returned to the transcript to identify quotations from the text to support the themes. This process was repeated for each transcript. The final stage of the analysis involved reviewing the identified themes and their supporting quotes to identify common themes (accommodating both areas of convergence and divergence) across the full set of transcripts to produce a final theme structure that encapsulated the data and findings.

Analytical rigour

Within this research, we used a number of procedures to ensure the rigour of the analysis. The first author took the lead in analysis and collaborated with the last author to produce an audit trail. To begin with, the first and last author listened to the first interview and discussed their separate analysis and interpretations of the data. This allowed both authors to 'sound out' each other for alternative interpretations and divergent evidence within the transcript. The

aim here was to identify our presuppositions and facilitate an openness to alternative interpretations. Having achieved these necessary sensitivities to analysing the data, the first author continued analysis of the remaining transcripts. As the analysis progressed, both authors met on a regular basis to discuss their independent analyses on a selection of the data. We compared and discussed each other's interpretations of participants' experiences. The aim of this process was not to provide an objectively true analysis, but rather to ensure that the analysis remained credible. The theme structure was also subjected to this dual scrutiny, with each theme being reviewed, discussed and points of consensus reached.

Reflexivity

Here we provide some reflexive detail regarding our guiding theoretical orientations and possible anticipations prior to data collection to help the reader identify and appraise any possible biases relating to the findings and conclusions of the study. The first author is a female Trainee Clinical Psychologist in her early thirties. In a previous role, she assisted with the development of a peer-support group for stroke. This provided her with insight into the challenges of developing a peer-support group. During the study, the researcher noticed that she experienced empathy towards the current service, acknowledging a desire for the group to be beneficial for participants. Furthermore, the charity expressed a keen interest towards the current research, and identified areas for improvement. Therefore, the researcher had to "bracket off" this information and her desire for the peer-mentoring service to be useful, allowing for "experience to be expressed in its own terms, rather than according to a pre-defined category" [18; p.32]. The second author is a clinical psychologist who works clinically with people with limb loss, while the third author is a health psychologist with extensive research experience relating to amputation and prosthesis use. In contributing to discussions regarding analysis and the implications of the findings these authors also engaged

in a reflexive process of identifying and keeping in abeyance one's own established understandings of the research topic. None of the authors had any prior relationship with participants or affiliation with the advocacy charity.

Results

Two overarching themes were identified: 'Developing a helpful self', and 'Connecting with vulnerability'. These are presented below supported by participant data excerpts (pseudonyms are used).

Theme one: Developing a helpful self

Within this overarching theme of 'developing a helpful self', we discuss the participants' cultivation of a valued and rewarding identity made possible through mentoring work. It is comprised of three subthemes that share a focus on the positive aspects of the interpersonal relationship mentors experienced with mentees: 'feeling valued through helping others'; 'creating and managing hope'; and 'the value of sharing lived experience with others'.

Feeling valued through helping others. Participants expressed a desire to help others and 'give back' support. This was expressed by peer mentors who had previously received support themselves and those that had not. Participants who had received support viewed this as a positive experience and wished to share this in their role as a peer mentor. For participants that did not receive support, there was a sense of unfairness and of 'missing out' on something important, and a desire for others to have an opportunity to access this. Rose explained this during her interview: "It wasn't available for me... and I feel quite strongly about that... I think it would have been helpful at that time, and it is something that I would have welcomed... to give people something that I couldn't have."

Participants reflected that although they enjoyed helping others, the experience of providing support was useful for them also, contributing to their wellbeing and adjustment to limb loss:

I like helping people...it can be a very traumatic thing... and more so mentally than physically... I think the opportunity of talking to someone who has come out the other side of what a recent amputee is going through hopefully would help them... I think it helped me...it made me feel better about... overcoming what can be described as a disability. (Dexter)

Participants felt valued and appreciated through offering support. Juliet witnessed a change in one individual's attitude following her visit. She spoke of the emotional benefits, describing pride in her role:

It's nice when you go and see someone and they are quite despondent and by the time you leave they are actually looking forward to going to the hospital for their next bit of treatment... and they are going to get better... it makes you feel quite good.

For some, relationships continued after they had finished offering support. This acted as confirmation that the support had been helpful and valuable. Grace described meeting an individual that she had previously supported, and the positive impact of this: "...She said it made such a difference... the conversation, that there was life after limb loss...and that was the first time I had feedback... it made it all worthwhile doing."

Other participants described a sense of purpose, or usefulness, through offering support. Some drew similarities between peer support and the role they occupied during their career:

... I still miss the job I used to do...when I go back and talk to people I think, “Oh, I miss that, I wish I could still do that”... it gives me a good feeling knowing that I could still be helping people. (Debra)

Creating and managing hope. Participants described a key function of peer support as to provide hope for the future and the realisation that there is “life after limb loss.” Debra visited individuals shortly after their amputation, and highlighted the benefits of modelling a successful future in instilling hope:

...I think for some people, seeing me sort of walk in, you know, quite normally because I don't use a stick... it's really helped them...it's really, really helped them.

Additionally, Dexter shared his experiences of demonstrating that life carries on after limb loss, suggesting that peer support could speed up the adjustment process:

I thought it would help them to have a chat with someone who knows what it's like, and who gets through life pretty well with a bit missing...if I could impart someone some of the things I had learnt and to help them see that...ultimately, you will be alright, and I like to think that I am helping people get to being alright... a little bit more quickly than they would have done.

Participants experienced hope themselves through offering support, suggesting a reciprocally beneficial relationship. Jack supported an individual that experienced a traumatic accident, describing his positive reaction to this encounter:

I went away from there in admiration of this person's... fortitude, their optimism.

In addition to experiencing hope, Jack was inspired and uplifted through witnessing another's motivation:

Seeing people have that drive and want to make something of their life and go with this principle that I have of life after limb loss...I find that heartening.

Participants described a positive impact on perceptions of their own amputation. For some, meeting with individuals facing greater challenges allowed them to feel optimistic about their difficulties, considering themselves more fortunate in comparison. This can be seen in Nick's account, who described his limb loss through a traumatic accident. He revealed his relief that this was sudden, comparing his experience favourably to those facing the prospect of an operation: "Imagine that you have an operation coming up in two or three weeks...I can't imagine how people face that...it was so easy for me." A process of positively reframing experiences took place through participants meeting with others that they considered less fortunate.

Although participants wished to inspire hope, there was careful consideration in managing expectations, and the desire to share realistic experiences was expressed. Participants were cautious to avoid providing false hope, and to counter unrealistic expectations regarding recovery. Juliet expressed concerns about recent media coverage of amputation, describing that an important function of peer support is for individuals to meet every-day peer mentors, in comparison to the "super people" seen on the television: "They do seem very positive... but they are not your regular nine to five...running a house, a mum with kids, or a dad going to work." Similarly, Dexter shared his experience of an individual who had unrealistic expectations for recovery:

His stump was quite swollen, and he was getting really fed up because it wouldn't go down, and I said, "How long ago was your amputation?". "Oh, a fortnight"... "Get a life, will you?"... a weight bearing part of your body is taken off...the body is trying to get back to normal... it doesn't happen overnight, and this guy wanted it to be immediate, he had seen... servicemen climbing Everest, or walking across the Arctic Circle in underpants and flip-flops... he thought it should be like that, and it isn't.

To overcome the potential for unrealistic expectations, some participants felt it was part of their role to share a direct and honest account of the difficulties they experienced. Grace described supporting someone considering an elective amputation: “He thought if he had an amputation he would be able to run like the athletes...I put him straight on that...the reality is not like that...”

The value of sharing lived experience with others. Participants felt they were in a unique position to offer support because of their lived experience of amputation. Grace explained: “An amputation is strange... unless you have had one you can’t understand what it’s like.” Through this shared understanding emerged a sense of belonging and connection, and the argument that peer mentors were in a stronger position to understand the challenges faced following an amputation. Although participants acknowledged the importance of professional help, they described that peer support differed to the support offered by medical professionals. Grace drew a distinction between the two: “Talking to somebody who has actually gone through it, it doesn’t matter how experienced doctors and nurses are... they can’t possibly know what it’s like.” Similarly, Rose considered the training that medical professionals received, arguing it lacked a unique quality that could only be accessed through direct experience:

Before you become disabled... you don’t understand, you see people that are disabled in the street... but you don’t understand their difficulties... not a clue how angry things make you, or how... frustrating life suddenly becomes... you can’t go on a training course and discover those things... because people learn things but they will come back and they still won’t know, because they can get on that ladder and change that light bulb, or do their garden, or whatever it is that you can’t do.

Through lived experience, participants could share practical knowledge based on their experiences of amputation. Jack described assisting a couple to understand phantom-limb pain, and their reaction to his support:

...Her eyes lit up, her partner started scribbling notes furiously, and she took the information away... to assist her in dealing with the issue moving forward, and that's happened on a good number of occasions...the best thing that has come out of my visits has been...providing an understanding of what phantom-nerve pain is.

Through sharing experiences participants assisted individuals to cope with various challenges and eased the adjustment process. Questions were asked about everyday challenges, and peer mentors were creative when providing advice, assisting others to consider new strategies and ways of managing difficulties. Participants conveyed a sense of duty and responsibility and were willing 'to go the extra mile' to provide support:

I have got a lot of self-help books that I have lent people... I also duplicate articles... give them a copy, it might be on phantom-pain, it might be on hygiene of the leg... so they feel that somebody cares really. (Debra)

Connecting with vulnerability

In the second overarching theme, 'connecting with vulnerability', we consider difficulties that working as a mentor presented for participants and how they managed these difficulties using the coping strategies available to them. These difficulties were identified and are presented across two subthemes: 'coping with uncertainty and self-doubt', which addresses the emotional challenges and costs faced by peer mentors; and 'sharing vulnerability and developing resilience', which concerns the impact of such challenges and costs on mentors' wellbeing and resilience.

Coping with uncertainty and self-doubt. Participants experienced a degree of uncertainty in relation to delivering peer support, and in particular, whether it was always useful for the person receiving it. Rose described offering support to an individual that was depressed, and questioned whether the visit was useful: “I was there at his mother’s request... he was very uninterested in what I had to say... I came away thinking that was a waste of time, although you don’t know because there is no feedback...” This reflects Rose’s uncertainty and frustration regarding the possibility that the visit was not worthwhile. This also extends towards the lack of feedback provided by the advocacy charity following a visit, and Rose highlighted the challenges of this in relation to adapting your approach when offering support:

I come away hoping that I have helped somebody ... you never get any follow up...it would be nice to know whether the person you have been to see found it helpful or not, what do they think you could have done better or whatever, to improve the experience for the next person.

Uncertainty was also expressed regarding the feedback that participants provided to the advocacy charity following a visit. Although the peer mentors were supposed to fill in a brief report for the service they volunteered for following a visit, Rose shared her reluctance to complete this due to uncertainty about sharing private information:

We are asked to do a report... I don’t always do one, I must admit, because I don’t really know what to say...because of confidentiality, there are lots of things you can’t say or shouldn’t say... so it’s difficult.

Debra discussed her own uncertainty in regards to how effective her mentoring role was, describing the value of the support she received from her husband. This appeared helpful for Debra as she was able to share doubts about visits and seek reassurance:

Sometimes I come away and... I am exhausted... when you go and see somebody that you don't know, you are anxious ...a couple of times my husband comes in and he can be quite funny...other times he is quite happy sitting in the car... so I have got a bit of a sounding board there...and I say, "I hope I helped them, I hope I have done it", and he says, "Oh, I am sure".

Grace also expressed uncertainty when offering support, and wondered how individuals experienced this. She questioned how she would have found the process, if it had been available:

I am trying to think how I would have felt if someone had come to see me, would I have been strong enough to say, "Go away", or "You're boring me, you're not telling me anything I need to know."

Other participants questioned whether recipients felt able to express a choice about the support they received. Nick discussed providing telephone support to an individual with depression. Despite several attempts, he was unable to visit this individual: "I was meant to be going to see him, but...I never actually knew where he was in hospital...obviously if he wanted a visit he would have had to say where he was.". Nick described contacting the advocacy charity to express his concerns; however, they were also unable to make contact. He expressed his hopelessness at being unable to help: "I didn't think there was much point, having tried two or three times to contact him and not getting hold...I thought... I probably can't do much more.". Referring to another occasion, Nick reflected on the challenges of offering support to one individual due to his level of distress: "He wasn't...very stable mentally...it was very difficult talking to him, he was very frightened... it was difficult to know what to say." Challenges regarding communication with distressed individuals arose across interviews.

Inconsistencies emerged regarding the training and guidance received relating to the role of a peer mentor, which appeared to contribute to uncertainty. While some participants received no training, others were given written guidelines. Additionally, Jack attended a half-day training event, provided by the advocacy charity, that he found useful:

We had a professional counsellor...the bit that I retain most strongly, was the counsellor saying, "We are not expecting you to provide counselling... you are not counsellors, you have loads of experience that you can share... and that's what we want you to provide"...I thought that was a very important message to get across.

Sharing vulnerability and developing resilience. Participants discussed the physical and emotional vulnerability involved in peer mentoring, and the challenges faced when offering support. Frankie referred to the limited support for peer mentors, potentially placing them at risk: "I think that's another thing they need to look at, it's not only protecting the amputees from us...we need protection... and that's one thing I will stipulate on, and it has never been mentioned." Key to the perception of risk were the physical vulnerabilities that accompanied limb loss: "I am only little anyway, and I do have a limp... I couldn't handle anybody that was bigger than me." (Frankie).

Participants also expressed emotional vulnerability during the interviews. Offering support reminded them of their own limb loss and difficult experiences. Juliet expressed anger about her amputation, which was the result of medical negligence: "It's very difficult to make anger go away because you know, it's something that was so life changing, and needn't have happened for me... it was because somebody made a wrong decision... that's very hard to live with." Despite this, Juliet felt that the counselling she received at this time had helped her come to terms with limb loss. Consequently, her experiences did not negatively affect her ability as a peer mentor.

Despite the reflection on their own amputation that peer mentoring stimulated, participants felt able to cope with the demands of offering support as significant amounts of time had passed since their amputations. However, some were still experiencing challenges even after many years, as Debra described: “Even now... 30 years down the line, I still get upset... I sometimes think, “Oh that’s not fair,” ...I think there are just some things that you think, “Oh, that wasn’t fair,” ...but I think there is still...the loss of something.” This seemed particularly relevant for Dexter, who became tearful during his interview when describing the impact on his mother. Later, he described the challenges faced during this time, and shared that “it took me a long time to get over it,” drawing parallels between his amputation and a bereavement process.

Previous experience in a challenging role helped some participants prepare for the emotional demands of peer support. Frankie described being mistreated by an individual that she attempted to support. When asked about this experience, she revealed exposure to challenging situations in a previous role, and how this helped her develop resilience: “I think I would have come away crying and wouldn’t have done anything again, but because I have done it for years, I was stronger, and it sort of went over my head in a way.”

Although previous experiences could present emotional challenges, Dexter suggested that showing vulnerability could be helpful for individuals receiving peer support, as it could normalise the difficulties faced following limb loss: “It’s possibly... a good thing that people see that it upsets me, because they know that they are not being weak if they have a cry... you are a bloody human-being...it’s normal to do that, it’s awful”.

Finally, vulnerability was considered in relation to individuals that received support. Some peer mentors questioned their assumptions regarding how individuals cope with the visit, and whether they approached the situation with enough sensitivity. This is apparent in Dexter’s appraisal of a recent visit: “I am beginning to doubt myself now, you know, have I

been too flippant? Have I been too black and white, and think everyone is like me? Because of course they are not...”

Discussion

Although previous research has considered the role of peer support in different contexts, there is limited literature exploring its usefulness for individuals with limb loss [11]. Furthermore, peer support literature on limb loss to date has focused on the experience of the individual receiving the support, rather than those delivering the intervention. The current research is the first study to consider the experiences of peer mentors who offer support to individuals with limb loss.

Participants reported benefits associated with providing peer support. Positive emotions were shared, such as: a sense of pride, purpose, usefulness, achievement, and feeling valued by others. Similar experiences of delivering peer support have been described within different health-related contexts [16] and the findings from the current research suggest providing peer support can also benefit individuals with limb loss.

Providing hope, and sharing a positive picture of ‘life after limb loss’, was a key function of peer support in the current study. Although the intention was to provide hope to individuals receiving support, the findings indicate that this was a reciprocal process, as peer mentors also experienced hope, motivation and inspiration through this interaction.

Additionally, participants described a positive change in how they perceived their own limb loss through peer mentoring. Through hearing the narratives of others, they began to find positives within their own experiences of limb loss, considering themselves as more fortunate in comparison. Social comparison theory may provide an explanation for the experiences reported by participants in the current study. This suggests that meeting peers can have a

positive impact, such as validating and normalising experiences, increasing self-esteem, and encouraging healthy coping behaviours [8].

Peer mentors coped with challenges in various ways. Some relied on support networks such as family, while others reported that the significant time that had passed since their amputation had facilitated adjustment. At the charity through which peer mentors were recruited, individuals wait two years before volunteering as a peer mentor, allowing time to adapt to limb loss. Participants in the current study may not have reported significant emotional challenges when providing support as sufficient time had passed since their amputation (for example, in a review of psychosocial adjustment to lower-limb amputation, Horgan and MacLachlan [1; p.837] found that ‘although depression and anxiety are relatively high up to 2 years post-amputation, they appear to decline thereafter to general population norms’). This highlights an important consideration for other services offering peer support, as allowing this time before volunteering may increase resilience and act as a protective factor for peer mentors.

Participants reported a sense of belonging and connection through sharing lived experience with individuals they supported. This is similar to findings from previous literature considering peer support groups for individuals with cancer, who reported a sense of belonging and an increased ability to cope with their illness [19]. The current findings demonstrate that belonging and connection can also take place within a one to one peer-relationship. For individuals with limb loss, this finding may be particularly important, as experiencing an amputation can lead to isolation and reduced social contact [3]. In the current research, it appeared that adopting a peer mentor role helped to reduce this isolation, allowing individuals to create meaningful relationships and connections with others.

Participants reported that lived experience placed them in a unique position to offer support, as they could share personal accounts and creative strategies based on their learning. Additionally, lived experience was considered valuable, as peer mentors could develop a deeper understanding of an individual's difficulties. Previous literature has suggested that peer mentors can offer increased empathy and validation when compared to medical professionals [10]. Although participants in the current study supported this, they considered both roles important. Participants reported that the peer mentor role added something unique, and was an important contribution to healthcare services. This finding may be particularly relevant to limb loss, as there is often a reliance by rehabilitation services on charities and additional services to provide emotional and informational support [20]. It may be that peer support could help to fill this service gap, helping to provide more holistic care for individuals with limb loss.

Physical vulnerability and consideration of risk emerged as an important finding from the current research. Although risk has been considered for peer mentors working within mental health contexts, there is limited literature within physical health settings [21]. In this research, several participants highlighted concerns for their safety when completing community visits. Although there is a general need to consider risk for peer mentors, this may be particularly important for individuals with limb loss who can face additional challenges, such as reduced mobility [2]. Recommendations may include meeting within public places for the initial visit and access to mobile telephones containing relevant numbers [6].

Participants described sometimes experiencing uncertainty regarding the usefulness of peer support, sharing confidential information and handling emotional distress. Challenges around risk management and handling confidential information may be difficult due to the dual-nature of peer support, where individuals are considered both a service user and medical

professional [6]. It has been suggested that training can make a positive difference to how peer mentors understand the role and cope with challenges [22].

Service-related implications

Based on the current study findings, recommendations can be made for services that seek to provide or input to peer mentor provision for people with limb loss. Participants expressed challenges and uncertainty mentoring individuals who were distressed or reluctant to engage. In regards to managing and responding to distress, participants wanted training on communication skills so they could learn how to respond appropriately. This could be incorporated into the training developed by peer services, providing opportunity for peer mentors to practice active listening skills to increase their confidence when encountering distress [12]. Although peer mentors are not intended to provide formal counselling or psychological therapy, knowing how and when to sign post or refer to appropriate services that can help in this regard would also be beneficial. It is also worth considering the risk of distress to the peer mentor through offering support. Although participants in this sample did not report experiencing distress, this may not be the case for all peer mentors at the current service. Therefore, information of relevant support services and contacts should be provided for the benefit of peer mentors too.

Participants expressed concerns about managing risk to themselves and others. It is important to provide guidelines to support peer mentors who have concerns over safety. This should contain information for who to contact at the service if peer mentors have concerns about an individual they are supporting. Additionally, risk to the peer mentor should be considered when completing community visits and strategies considered to minimise risk [6]. In the current study, although participants inform the service that a visit will take place, they

do not give exact information about when and where this occurs. One way to reassure peer mentors regarding personal risk would be to communicate this information to someone (most likely someone at the providing service) who monitors the visit and confirms safe return.

Participants in the current study reported inconsistencies regarding the amount and type of training they received. This resulted in uncertainty and frustration in how the service operated. To address this, peer mentors should all receive the same training, containing information regarding how the service operates, and why peer mentoring policies are in place. It is important to define clearly the role of a peer mentor and the responsibilities this involves. Some participants expressed wanting to meet other peer mentors and it was suggested that this could increase learning and skills, helping to establish a supportive network [22].

Finally, participants wanted feedback following visits. Participants were keen to know whether the service they provided was useful, and how they could improve this. Providing feedback could aid participants to feel more confident about the support they provide, whilst reassuring the service that the peer mentor role is valuable and contribute to its ongoing development and implementation.

Limitations and future research

A main critique of the current research relates to sampling. Most participants were over 60, and it is possible that their experiences differ to that of younger individuals. Although this could highlight a limitation with this particular sample, it does reflect the typical age of individuals experiencing amputation, as most individuals are older [23]. Participants identified themselves as 'white British.' The experiences of individuals from other backgrounds and cultures may have been different to this sample, and could have added an

important contribution to the findings. The cross-sectional nature of data collection means that participants' experiences were not explored over time. Such an approach would be useful in identifying, for example, any benefits or disadvantages of peer mentoring as they arise (and which might have been given less prominence here due to a reliance on participants' recollections). Given the tentative suggestion herein that peer mentoring work can have psychological benefits for people with limb loss (for example, through making positive social comparisons), future research could empirically test this through quantitative designs that compare samples of people with limb loss who do and do not volunteer on well-being measures (such as self-esteem and adaptive coping).

Conclusion

Previous research has indicated that peer support is a desired part of rehabilitation following amputation. However, there has been no previous research on peer mentors' experiences of supporting people with limb loss. The findings highlight benefits in providing peer-support, along with considerations when creating peer mentoring services for people with limb loss. The need for such services to provide clear and consistent guidelines regarding the peer mentoring role emerged. Recommendations have been provided within this research, which can be addressed through the development of training packages. This would provide the opportunity to address areas of uncertainty, and could also provide guidance around challenging aspects of the role, such as supporting individuals experiencing distress and managing issues of risk and confidentiality.

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Table 1. Participant demographic information

| Pseudonym | Gender | Age | Time since amputation (years) | Type and cause of amputation | Length of time as a peer mentor (years) |
|-----------|--------|-----|-------------------------------|---|---|
| Debra | Female | 57 | 14 | Right leg, below knee; Osteomyelitis | 12 |
| Dexter | Male | 60 | 41 | Left leg, below knee; Motorcycle accident | 15 |
| Frankie | Female | 63 | 24 | Left leg, above knee; hyperlipidemia | 2 |
| Grace | Female | 62 | 18 | Right leg, below knee; road traffic accident | 2 |
| Jack | Male | 60 | 36 | Right leg, above knee; road traffic accident | 10 |
| Juliet | Female | 64 | 11 | Right leg, above knee; medical negligence | 6 |
| Nick | Male | 63 | 7 | Through-hip; workplace accident | 3 |
| Rose | Female | 56 | 48 | Right leg, below knee; medical complications following a broken leg | 4 |

Appendix A. Interview schedule

How did you become aware of the peer support service?

- What were your initial thoughts when you heard about it?
- Did you have any worries or concerns before joining?
- Did you have any hopes before joining?

Can you tell me about your experiences of offering peer-support?

- Can you tell me a little more about that?
- What are your thoughts about that?
- Why was that?

What would you describe as the key function of the peer-support?

- What are the important features of this service?
- Why?

What is your opinion of the peer-support service?

- What do you think of the service?
- How do you feel about the service?

Why do you continue to offer peer-support?

- What do you get from offering this support?
- Is there a particular reason you want to keep offering this support?

Have you experienced any problems or limitations to offering the support?

- Can you tell me a bit more about that?

How would you like to see the peer-support service develop in the future?

- Do you have any recommendations?
- Any hopes for the service?
- Any changes that you would like to see?