March 2024

The Benefits of Peer Visitation on the Rehabilitation of New Amputees: A Qualitative Study

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Abstract
Purpose: For the purpose of this study a peer visitor is being defined as someone who has experienced some type of limb loss and is now mentoring other amputees. Their focus is on health and recovery as opposed to illness as they listen, provide emotional support, and most importantly inspire hope in an individual who has experienced a new amputation. The primary purpose of this study is to examine the reports of amputees regarding their personal experiences related to whether they spoke with a peer visitor following surgery. The study focuses on the benefits of peer visitation and how it impacts rehabilitation outcomes. Methods: This study utilizes a qualitative methodology, and in response to the research questions the benefits of phenomenological research will provide thoughtful and compelling representations of the different lived experiences from all participants. The sample for this study was drawn from across the U.S with the assistance of a local Hanger Inc. clinic, and the Amputee Coalition of America. The primary data collection tools for the investigation were in-depth, audiotaped interviews and a pre-interview questionnaire. All interviews were conducted either over the phone or through a Zoom platform. Results: Findings revealed that peer visitation improves coping strategies for anxiety and depression following surgery, increases confidence and hope in the patient, and influences mental health recovery. Conclusions: Based on the findings it was concluded that a peer visitor will improve overall mental health, improve patient attitudes, and overall improve rehabilitation outcomes for new amputees, and it is plausible to generalize these conclusions to the entire population of amputees. This study empowers new amputees and healthcare practitioners with knowledge to seek out a peer visitor following surgery, as it can improve the outcome of the patient's rehabilitation.

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Acknowledgements
The recruitment of subjects was facilitated by Tim Curran of Hanger Clinic in Worcester, MA. The conceptualization and design of this investigation was aided by Alex Tomaszewski of Hanger Clinic of Maine.
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This manuscript is available in Internet Journal of Allied Health Sciences and Practice: https://nsuworks.nova.edu/ijahsp/vol22/iss2/23
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ABSTRACT

Purpose: The primary purpose of this study is to examine the reports of amputees regarding their personal experiences related to whether they spoke with a peer visitor following surgery. (For the purpose of this study, a peer visitor is defined as someone who has experienced some type of limb loss and is now mentoring other amputees. Their focus is on health and recovery as opposed to illness as they listen, provide emotional support, and most importantly inspire hope in an individual who has experienced a new amputation.) This study focuses on the benefits of peer visitation and how it impacts rehabilitation outcomes. Methods: This study utilizes a qualitative methodology, and in response to the research questions, the benefits of phenomenological research will provide thoughtful and compelling representations of the different lived experiences from all participants. The sample for this study was drawn from across the U.S with the assistance of a local Hanger Inc. clinic, and the Amputee Coalition of America. The primary data collection tools for the investigation were in-depth, audiotaped interviews and a pre-interview questionnaire. All interviews were conducted either over the phone or through a Zoom platform. Results: Findings revealed that peer visitation improves coping strategies for anxiety and depression following surgery, increases confidence and hope in the patient, and influences mental health recovery. Conclusions: Based on the findings it was concluded that a peer visitor will improve overall mental health, improve patient attitudes, and overall improve rehabilitation outcomes for new amputees, and it is plausible to generalize these conclusions to the entire population of amputees. This study empowers new amputees and healthcare practitioners with knowledge to seek out a peer visitor following surgery, as it can improve the outcome of the patient's rehabilitation.

Keywords: amputee, limb loss, peer visitor, peer support, physical rehabilitation
INTRODUCTION
Regardless of race or ethnicity, an individual’s perception of their personal body image is an integral part of how they see themselves in society. This perception incorporates one’s ego, their perception of their place in the world, and how they believe others understand and recognize them. However, changes to an individual’s body (i.e., limb loss) can alter one’s self-image which can lead to limitations in the performance of social, professional, and recreational activities.1,2

In many instances, amputation can improve a person’s quality of life and daily function. Chronic and progressive lower limb ischemia or infection can cause pain and movement limitation, which can impact an individual’s ability to complete everyday tasks. In such cases, amputation surgery can improve one’s functional ability. However, even in the presence of reduced pain and improved mobility, the fact remains that the human body has been altered, causing a change in the individual’s perception of their self-image.2,3,4

One reason for the change in self-awareness is the overall dominance of the biomedical model, which focuses on the separation of mind and body. However, due to the growing recognition related to the importance of holistic treatment, the integrated biopsychosocial model is currently the accepted and recommended approach. This model allows for mind, body, and relations to be addressed in concert with one another.1,2,3,4 The current literature indicates that there is a strong link between psychosocial adjustment and physical rehabilitation, which means that an individual who has challenges with their body image will not be as prepared or motivated to reach their highest level of function.3 Conversely, an individual who has reached acceptance of their current self-image is more likely to return to their previous activities as well as exploring new ones.1

Currently, there appears to be a dearth of literature regarding research of limb loss and its subsequent impact on body image in a physical rehabilitation setting. Compounding this problem is the general public’s misconception regarding prosthetic limbs and their respective functional levels. For example, there is always a great deal of publicity that surrounds an individual with a prosthetic limb who runs the Boston Marathon or who climbs a mountain. This publicity, however, skews the public’s perception, preventing them from realizing the emotional impact that limb loss has on all individuals.3,5

According to the Amputee Coalition of America it is completely normal and understandable for a patient to lament the loss of a limb.4 Not only is it a natural process, but it is beneficial and essential for the person to progress through the grieving process when any loss occurs.4 Patients who suddenly experience this loss are affected both psychologically and socially, having to face conditions that include anxiety, depression, and self-isolation. Repression of these feelings can serve as a detriment to advancement and can have a significant influence on body image and self-esteem.2 At a time like this, there is a considerable need for emotional support, and this is where the benefits of a peer visitor are realized.4,6

The peer visitation support system was created for the amputee population and consists of a network of individuals who also experienced a form of limb loss and are now mentoring other amputees. These individuals have experienced rehabilitation, and a subsequent reintegration into society. The relationship that is created provides invaluable emotional, informational, and social support that often leads to a collaborative development of skills and knowledge for the patient.6,7 Peer visitors receive formal training which places an emphasis on the importance of communicating with, and learning from, individuals of similar age, indication for amputation, and level of amputation. The peer-to-peer support program for people with limb loss is sponsored by Hanger Clinics across the country and is referred to as AMPower. The training prepares people who are successfully living with limb loss to serve as role models and to provide encouragement for people who have recently undergone amputation surgery.6 The training ensures that an individual with limb loss is getting the most valued information that pertains to them, and it assists them in the process of coming to terms with their new lifestyle, as well as supplementing and maximizing the benefits of rehabilitation.6,7

The AMPower Peer Support training acknowledges the range of emotions that potential patients may be feeling, and it also provides detailed education for individuals wishing to become an effective peer visitor. The first basic principle of the training deals with an individual’s ability to communicate.8 Good communication skills are essential for a successful peer visitor. Patients typically have varying levels of interpersonal skills, especially following amputation surgery, and a peer visitor may have to work at fostering good conversation with many of their patients.8 The training will also describe how to support a patient through the healing process. People who undergo amputation surgery may experience a broad spectrum of emotions, and not all of these emotions may be due to the physical loss of the limb. The patient’s emotions may also incorporate career, family life and re-socialization. Training ensures that the peer visitor will become knowledgeable in how to assist patients who are dealing with these emotions.8 Most importantly, AMPower training helps a peer visitor in the management of difficult situations. As an example, how does a peer visitor interact with a silent patient? Learning not to force the conversation, and providing encouragement to the patient to take their time will help in nurturing a patient’s confidence and trust. Sensitive matters such as sexuality and intimate relationships, and a patient’s possible thoughts of suicide are covered in depth during the training.8

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While there is a plethora of studies regarding amputees from a physiological and anatomical perspective, a thorough review of the existing literature surrounding peer visitation for individuals with limb loss revealed a very small number of studies addressing the topic. The lack of research on the impact of peer visitation on an amputee’s rehabilitation necessitates further exploration. Therefore, the purpose of this study is to examine the reports of amputees regarding their personal experiences related to peer visitation, or the lack of peer visitation, following amputation surgery.

METHODS

Subjects
A purposeful sampling strategy was employed for this study. The participants for this research were recruited from across the United States with the assistance of a local Hanger Clinic in Worcester, Massachusetts, and with the support of the Amputee Coalition of America. There were twelve people (7 males, 5 females) who participated in this research investigation. Six of the participants received peer support (Group #1) following their amputation surgery, while the other six participants (Group #2) did not. It should be noted that the six participants who did not engage in the peer visitation program did so because they were unaware that this program existed. All twelve of the participants experienced lower extremity amputations, and they were all actively using a prosthetic limb at the time of the interview. The average age of the twelve participants in the study was 55.1 years.

The primary inclusion criteria for this investigation were that the participants must have experienced an amputation of disease or trauma-related origin. Seven participants experienced disease-related amputations, while the other five participants’ amputations were due to trauma or accident. The average length of time between the interview and the participants’ amputation surgeries was 8.4 years, and all participants had experienced lower extremity amputations.

Procedures
The primary data collection tools for this investigation were in-depth, audiotaped interviews along with a pre-interview questionnaire. The pre-interview questionnaire, the proposed interview and the informed consent form were all piloted. The feedback that was generated by the pilot interview spawned minor changes in the interview questions that addressed order and clarity. The pilot-test group consisted of one individual with limb loss who took part in the peer visitor program. The data collected during the piloting was not included as actual data in the study. The questionnaire consisted of demographic information for each subject, as well as questions that were intended to prepare each subject for the interview by having them recall their amputation surgery.

Data Collection
An in-depth, focused interview was conducted with each subject. The interviews were guided by an open-ended interview protocol that was developed based on the research questions, the primary investigator’s experience as a physical therapist, and from the existing literature regarding the rehabilitation of individuals with limb loss. The interview approach used in this study outlined a set of situations and considerations, and then allowed the participant to respond to, and expand upon, the questions that were posed by the interviewer.

At the beginning of each interview, a statement was read explaining the purpose and nature of the interview in addition to getting the participant’s formal consent to participate. The interview protocol was followed implicitly for each interview. Interviewees were asked to provide their introductory information, along with information concerning the impact and influence of the subject’s amputation experience. All interviews were performed by phone or over a Zoom platform due to the impact of the COVID-19 pandemic. Three members of the research team conducted the interviews with strict adherence to the interview protocol, and each interview was recorded and transcribed for future coding and analysis.

Data Analysis
The primary source of data for this study was the focused interview that was conducted with the participants who had experienced limb loss. The transcribed interviews were analyzed to get a general impression of the content. A list of themes was compiled based on the similar and different aspects of each subject's experiences. The main theme, transference of knowledge (regarding mindset, coping strategies, and rehabilitation process), was established, with the sub-themes of relatable experiences as described by the subject.

Data display is the step of analysis during which the data was systematically organized into charts, which were supported by illustrative quotations from the transcripts. The final step of the data analysis was conclusion drawing and verification where decisions were made about the findings of the study.
RESULTS
The participants in this study represent five distinct and separate geographic areas of the United States—New England states (2), mid-Atlantic states (3), north central states (2), southwestern states (2), and West Coast states (3). The participants came from various backgrounds and were experiencing varying levels of functional activity. Group #1 (group that received peer support) started using their prosthesis 4.3 months after surgery on average, while Group #2 (no peer support) began using their prosthesis 6.5 months after surgery on average.

Regarding the question of how peer visitation affects health related outcomes for new amputees, 8 of the 12 participants (67%) identified coping strategies for anxiety and depression that follow the surgery. Peer support not only aids in reducing fears and anxieties about the recovery process, but it promotes an emotional well-being that leads to a decreased incidence of depression. Participants who received peer visitation stated that they would have easily experienced increased levels of anxiety following their amputation surgery had it not been for the support provided by their peer visitor. One participant who received peer visitation was quoted with the following statement:

“I would’ve been much more depressed about where I was… And it’s not hard to get depressed. [peer mentor] helped me… I didn’t have anyone else who could do that. So, he was the sole provider of how to deal with it mentally…”

This same sentiment was supported by the participants who did not receive a peer visitor. Those participants felt that their increased anxiety and depression levels could have been calmed by the guidance of a peer visitor. One of the participants who did not receive peer visitation stated the following:

“You’re already suffering with depression and anxiety, and you are very aware that you’re missing something… my recovery would have gone quite a bit better if I had a support person share how they dealt with the depression…”

Even though it was only recognized by 4 participants (33%), reintegration into society was identified as a second major theme for this question. The literature states that peer support helps to improve the quality of an amputee’s social relationships. Participants who received a peer visitor revealed that they gained a sense of comfort and willpower that helped them throughout their recovery. The following quotation comes from one of the participants who did not have a peer visitor following surgery.

“If I had been able to talk to somebody, you know, someone who was active—I think that would have helped me in my journey, but not just from a physical aspect, from a networking aspect also. I really enjoy meeting people and working with people—just the whole aspect of engaging with the community, so that would have been another positive aspect of having a peer visitor.”

Two major themes were generated with respect to the question of how peer visitation benefits an individual who has experienced limb loss for the first time. Eight of the twelve participants (67%) identified enhanced guidance through shared experiences as one of those themes. It was revealed in the interviews that by receiving emotional support from a peer visitor who had experienced a similar fate, a patient could adjust their own recovery based on the living example of the peer. The following quotations confirm what has been stated:

“The role that my peer visitor played initially—only he could have played it. There was no one else in my life who could have done for me what he did.”

“I would’ve liked to have talked to someone who was like me—an above the knee. I would’ve asked what’s life like right now as opposed to before the amputation.”

The second major theme that was brought up dealt with the provision of knowledge a peer can provide to a patient. Surprisingly, this was only mentioned by five of the twelve participants (42%). The interviews showed us that a peer visitor could provide both general and intimate knowledge regarding some of the most mundane of activities. Driving, using a public bathroom, or being intimate with a partner were some of the topics of discussion; while the individuals who did not have peer support wanted to hear about the “tips and tricks” of how to progress toward their “new normal.”

“I firmly believe that knowledge is best when it is shared, so I needed to find someone who would share their knowledge with me and let me know if my expectations were realistic.”

The last question (How does peer visitation affect an amputee’s expectations for a full recovery?) revealed one major finding and was mentioned by seven of the twelve participants (58%). It was discovered that a peer visitor elevated a patient’s confidence and
expectations, leading to better outcomes.\textsuperscript{7} These findings confirm the results of previous investigations that peer visitation improves an amputee’s confidence in their ability to navigate life’s daily activities, as seen in the following quote:\textsuperscript{7,10}

“I would never be where I am without him. I would never be this independent, this confident…And just being around people who are just like you, because you feel like such an alien after the surgery, and to know that you’re not alone, I would say is the number one part of peer support that really changed me and gave me my confidence back.”

This will benefit an amputee throughout the rehabilitation process which in turn will lead to enhanced participation and goal achievement.

An isolated finding (three of the twelve participants) that was generated out of the responses for this question is that the attitude or personality of the peer visitor can significantly impact the rehabilitation and overall mindset of the patient. Messinger et al. shows that peer visitors with similar experiences to the patient improves the rehabilitation process in both function and timeline.\textsuperscript{7} It is also reported that individuals with differing attitudes or functional goals can result in decreased satisfaction and diminished outcomes, which the following quotation supports:

“First of all, I was still in a lot of pain and in the hospital, and my peer visitor wasn’t the greatest at conveying support or hope. He used his wheelchair all the time and he didn’t wear his legs a lot. So, to me, that wasn’t really what I wanted to hear or was looking for.”

Tables 1, 2, 3, and 4 represent the themes that were generated for each research question.

Table 1: Research Question #1—How does peer visitation affect health related outcomes for new amputees?

<table>
<thead>
<tr>
<th>Codes</th>
<th>Group #1</th>
<th>Group #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved connection to social support</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Coping strategies for anxiety and depression during recovery</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Mental health recovery</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Table 2. Sub-Question #1—How does peer visitation benefit an individual who is experiencing limb loss for the first time?

<table>
<thead>
<tr>
<th>Codes</th>
<th>Group #1</th>
<th>Group #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides knowledge</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Enhanced guidance through shared experiences</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Table 3. Sub-Question #2—How does peer visitation affect an amputee’s expectations for full recovery?

<table>
<thead>
<tr>
<th>Codes</th>
<th>Group #1</th>
<th>Group #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer visitor having a different mindset/attitude</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Increased confidence and hope leads to better outcomes.</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Provides an example of successful rehab and return to “normal” life/activities</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Table 4: Sub-Question #3—How does peer visitation affect amputee knowledge during the recovery process?

<table>
<thead>
<tr>
<th>Codes</th>
<th>Group #1</th>
<th>Group #2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1P</td>
<td>2P</td>
</tr>
<tr>
<td>Functional knowledge</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Prosthetic knowledge</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

**DISCUSSION**

Peer support by way of visitation improves multiple aspects of a new amputee’s recovery process and attends to all elements of the biopsychosocial model.\(^{11,12,13}\) This investigation suggests an improvement in functional and prosthetic knowledge, which, in turn, eases an amputee’s fear and anxiety relating to the future. This is, to some extent, validated by the fact that participants who met with a peer visitor experienced a shorter duration of time from the onset of surgery to the start of their prosthetic use.

Messinger reported that peer visitation provides the amputee population with a sense of what their own recovery trajectory will look like, especially when the peer visitor has had a common or similar experience.\(^7\) Shared similar experiences between peer and patient allows the patient to orient their own recovery trajectory and be witness to a living example of what their future may look like.\(^{10,14}\)

Participants in this study who engaged in peer visitation expressed a greater quality of societal relations, which encouraged involvement in peer groups and consequently opened other doors for new opportunities. Sixty-seven percent of all participants identified that having a visitor with a similar amputation experience and of similar age and gender provided, or would provide, a greater benefit and improved connection, which in turn would result in a healthier outcome.

According to Reichmann, peer support is vital for any functional rehabilitation, but it is especially critical in the realm of mental health and social integration.\(^{9,11,12}\) Most of the participants who met with a peer visitor reported that they experienced improvements regarding their overall emotional and mental health. This finding is crucial as it bolsters a new amputee’s self-esteem and self-perception as they progress through their course of recovery.

However, there is evidence that supports an amputee’s mental and emotional health in the absence of a peer visitor. In this ethnographic study, Hoffman observed lower limb amputees throughout the rehabilitation process during which body normalcy was reconstructed.\(^{15}\) Throughout the process, physical therapists, playing the role of social agents, teach practical and informal techniques to their patients to manage both body and prosthesis. Findings revealed that the use of the term “prosthesis” is inadequate because it ultimately defines an individual as someone with limb loss lending itself to a negative body image. To avoid such stigmatization, the therapists and associated staff teach compensatory skills which enables the incorporation of the prosthesis into a functional skillset, all while referring to it as a biological leg in the re-cultivation of body techniques.\(^{15}\) According to Hoffman, the paradox that exists is that the prosthesis, which is meant to benefit the patient, also induces pain and discomfort—a fact that challenges its overall acceptance by the patient.\(^{15}\)

This study makes a significant contribution to the ongoing theoretical debate regarding the relationship between the biological and the social in disability studies. These findings indicate the need to incorporate both the cultural and the physical in the exploration of disability, and the ethnography of disability should be viewed as a juncture of socio-cultural perceptions of the body, embedded in its own bodily constraints.\(^{15}\)
LIMITATIONS
In this study, there were three weaknesses. The first limitation was that all the participants had experienced a lower extremity amputation. While it is plausible to apply these findings to the overall population of amputees, it is difficult to generalize the results to individuals who experience upper extremity limb loss. The second limitation was that neither the frequency nor the length of time of the visits by the peer visitor to the patient was documented. Learning the specific details of a mentor’s visit with the patient would have provided a better understanding of how a peer visitor empowers the new amputee, providing new insights for other peer visitors. The third limitation is that the primary investigator developed the interview guide, and the instrument was pilot tested. However, it was only pilot tested once, and because it was never used in any previous study, its reliability and validity come into question.

RECOMMENDATIONS
Since all the participants in this study were individuals who had experienced lower extremity limb loss, it is important to follow up with a study that investigates upper extremity amputees. The upper extremity is one of the most important parts of the body that possesses functional ability to perform daily activities, self-care duties, hobbies, and sports. The rehabilitation practices for an individual with an upper extremity amputation differ greatly when compared to an individual with lower extremity limb loss. Rehabilitation is directed at an individual’s functionality and satisfaction with their prosthetic device, as well as increasing self-care independence which provides success with the prosthesis.17 A quantitative follow-up study would be the next logical step to aid in further understanding all the qualitative data from both populations.

CONCLUSION
This study examined the reports of two groups of amputees—one group that received peer visitation and one that did not. Given the results, it appears that peer visitation improves the overall mental health and attitude of a new amputee by providing coping strategies for anxiety and depression. With an emphasis on health and recovery, a peer visitor can also impact a new amputee’s perspective through experiential knowledge which fosters confidence and hope during recovery; this subsequently accelerates the individual’s reintegration into society.11,12,13,16

Some of these findings reaffirmed the latest evidence, while some of the other findings created new questions. Since this study drew on only two different groups and a relatively small number of subjects, the conclusions must be viewed as tentative. Nevertheless, it is plausible that the conclusions generalize to the wider population of all amputees where the findings will be clinically relevant providing evidence to practitioners that peer visitation is a meaningful addition to a patient’s continuum of care and should be considered a component of any new amputee’s care plan.

REFERENCES:


