Engagement in activities revealing the body and psychosocial adjustment in adults with a trans-tibial prosthesis

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Abstract

The purpose of this study was to examine the effects of the appearance of a prosthesis on social behaviour, social discomfort and psychological well-being in eleven amputees taking delivery of a prosthesis with a silicone cover. Two new scales were developed: the ‘Engagement in everyday activities involving revealing the body’ (EEARB); and the ‘Discomfort-Engagement in everyday activities involving revealing the body’ (Discomfort-EEARB) scales. The psychometric properties of these scales were determined using a sample of 101 able-bodied adults. The Hospital Anxiety and Depression Scale and the Rosenberg Self-Esteem Scale were also used to measure psychological well-being in the amputee sample.

The EEARB and Discomfort-EEARB proved to have good reliability and validity. Comparison of amputees’ scores prior to receiving the silicone cosmesis with those of the able-bodied adults revealed significant behavioural limitations and social discomfort, associated with low self-esteem, anxiety and depression. There was a significant increase in amputees’ scores three months after taking delivery of their prosthesis, indicating that amputees reported engaging in more activities which involved revealing their body, and that they would feel more comfortable in situations which involved revealing the body. As the amputee sample available was small and self-selected, it is not possible to generalise these findings to the amputee population as a whole. However, since there is little previous research investigating the effects of the appearance of the prosthesis, these findings demonstrate the need for further research in this area.

Introduction

Although amputation normally serves as a lifesaving measure (Rybarczyk et al., 1992), a growing body of research has shown that a significant number of amputees are confronted with psychological adjustment problems (e.g. Kashani et al., 1983). It is estimated that approximately one in three hundred people in western countries undergo major amputation (Rybarczyk et al., 1995) and so psychological adjustment problems within the amputee population may be viewed as a significant health problem. Moreover, poor psychological adjustment may influence the involvement and performance of amputees during rehabilitation and affect their prosthetic rehabilitation in the long term (Engstrom and Van de Ven, 1999).

Ninety per cent (90%) of all amputations conducted in the UK involve a lower limb (Bradway et al., 1984). Psychological adjustment problems common among adults who have undergone leg amputation include depression, anxiety, low self-esteem, loss of a sense of wholeness, and social isolation (Frierson and Lippmann, 1987; Kashani et al., 1983). Kashani and colleagues (1983) reported clinical levels of depression in 35% of patients following leg amputations. Longitudinal research has also found that significant levels of psychological morbidity and social isolation, which were present immediately after the amputation, were still apparent in over 40% of the sample at one and two year follow-up periods (Thompson and Haran 1985). More recent studies have shown that amputees with
high levels of depression are less likely to adopt an active problem solving approach, which may affect their long-term rehabilitation (Livneh et al., 1999).

Other studies have highlighted an important association between psychological adjustment problems following amputation and feelings of social discomfort and stigma (Rybarczyk et al., 1992; 1995). Rybarczyk and colleagues (1992; 1995) found that the degree of social discomfort experienced by a patient following amputation was a significant mediator of psychological adjustment. Their social discomfort measure involved asking amputees whether they were bothered by public enquiries about their amputation or prosthesis, and if they avoided being in public because of their amputation or prosthesis. It was found that high levels of social discomfort were significantly correlated with clinical depression; indeed, 73% of participants could be correctly classified as being ‘depressed’ or ‘non-depressed’ by using a cut-off score on the social discomfort scale (Rybarczyk et al., 1992). In a second study conducted by Rybarczyk and colleagues (1995) similar results were reported, again showing that amputation-related body image concerns and perceived social stigma were significant and independent predictors of depression. This consistent association between feelings of social discomfort, stigmatisation and psychological morbidity demonstrates how leg amputation can leave individuals feeling flawed and socially isolated (Charmaz, 1999).

More recent research exploring amputees’ thoughts about their amputation found that many amputees believed that taking delivery of a prosthesis was important in restoring and normality back into their life (Gallagher and MacLachlan, 2000). However, some amputees expressed concerns about the design and appearance of their prosthesis. A later study and conducted by Gallagher and MacLachlan (2001) found that ‘self-image’ was one of the dominant themes which emerged from focus group discussions with lower limb amputees. In the discussions, amputees highlighted their concerns regarding their public appearance, and their wish to appear normal. Social interaction was also highly relevant; amputees frequently found people’s reactions to their prosthesis hard to deal with, and this could be a particular concern in the early stages of a relationship. Amputees believed that the appearance of their prosthesis was an important issue in establishing a positive self-image. Research carried out by Fisher and Hanspal (1998) found that amputees who were moderately satisfied with their prosthesis had little experience of body image disruption or distress. This study also found that attitude towards the prosthesis was not associated with mobility, which therefore suggests that although amputees may have a good level of mobility, they may still be unsatisfied with their prosthesis. It is therefore possible that other issues, such as the appearance of the prosthesis, are important to the amputee.

Despite this evidence of the importance of the appearance of the prosthesis to the psychological well-being of some amputees, to date there has been limited published research investigating the effects of the appearance of different prostheses on psychological adjustment. This may be considered surprising, as during the last decade, advances in the cosmetic appearance of prostheses have led to the development of cosmetic covers for prostheses which are remarkably similar to the contralateral limb. Silicone cosmeses are made to match an amputee’s skin colour and can be produced with skin creases, freckles, veins and finger/toe nails to provide an extremely realistic looking limb. The appearance of the prosthesis will undoubtedly affect the amputee’s ability to disguise his or her disability. It has been suggested that by doing this, individuals may preserve the sense of unity between the body and self which had been established before their disability (Charmaz, 1999).

The purposes of this study were threefold. The first was to develop and validate two new scales designed to assess behaviour and discomfort in situations involving revealing the body. Although two recently developed body-image scales have been used within the amputee population, these were not designed to assess thoughts and behaviours specifically relevant to the appearance of the prosthesis. The ‘Body-image Questionnaire’ developed by Fisher and Hanspal (1998) derives from a body shape questionnaire used in eating disorders (Cooper et al., 1987) and assesses the amputees’ level of satisfaction with their body image. Although this scale provides the respondent with the opportunity to assess whether the prosthesis has restored their body shape (Fisher and Hanspal,
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1998), it is focussed on the body shape and body image in general and does not assess specific feelings associated with revealing the body (and therefore the prosthesis) or related activities which involve revealing the body. The ‘Amputation-Related Body Image Scale’ (ARBIS) (Rybarczyk et al., 1995; 1992) is an 11-item scale asking amputees about their thoughts and behaviour during the last six months. Although this scale includes some questions relating to how the prosthesis looks and levels of social comfort, the context of the scale is quite broad as it also includes questions relating to the stump and amputation.

Having developed and validated scales to specifically measure social discomfort and behaviour relating to the appearance of the prosthesis, the authors’ second aim was to evaluate whether amputees’ self-reported levels of engagement in these activities, and discomfort and psychological well-being, changed after taking delivery of a prosthesis with a more realistic appearance (i.e. a silicone cosmesis) than their previous prosthesis. The third aim of this study was to compare amputees’ scores before and after taking delivery of their new prosthesis with scores in a normal population sample.

Method

Sample

To test the properties of the questionnaires and provide normative data for comparison with the amputees’ scores, a normal population sample of 101 able-bodied adults was recruited. This group consisted of an opportunity sample of 59 females and 42 males from within the Southampton area. The age range was 18 to 60 years (M=29.8 years; SD=9.5).

The amputee sample comprised all trans-tibial amputees consecutively attending an Independent Limb Centre over a six-month recruitment period for their first fitting of a prosthesis with a silicone cover. Only 1 out of the 11 amputees was an NHS referral, the rest of the amputees were private patients. The group consisted 10 females and 1 male in an age range of 19 to 59 years (M=37.4 years; SD=12.34). With regard to the causes of amputation: 3 were secondary to vascular disease; 5 to trauma; 2 to cancer; and 1 was congenital. Recruitment to this study was on average 7.5 years after their amputation (range, 9.5 months to 34 years). All subjects had previously been fitted with a non-silicone prosthesis.

Measures

The questionnaire pack contained two standard measures of psychological wellbeing and two body-image scales, which were developed for the purpose of the study by a team which included a female amputee with experience of psychological research, a health psychologist with expertise in questionnaire development, and an experienced prosthetist.

The Engagement in Everyday Activities involving Revealing the Body scale (EEARB) is a ten-item scale, measuring how many times in the last three months respondents engaged in different activities which involved revealing their body (see Table 1). Responses range from 0='not applicable', 1='never', 2='1 to 3 times a month', 3='once a week', 4='1 to 3 times a week', 5='4 to 6 times a week', and 6='daily'. A total score is obtained by adding scores from the individual items together; possible total scores range from 0 to 60. As the EEARB scale contains two items (items 2 and 4) which specifically refer to individuals with a romantic partner, the design of the questionnaire required respondents without a romantic partner to select the ‘not applicable’ option and therefore score 0. Therefore when a 0 is scored it was necessary to recalculate the score, and as EEARB scale is a ten item scale, this was achieved by multiplying the relevant participant’s total scores by 10, and then dividing it by eight.

The Discomfort related to Engaging in Everyday Activities involving Revealing the Body scale (Discomfort-EEARB) is an eleven-item scale requiring respondents to imagine they are undertaking each of the activities in the EEARB which involve revealing their body and rate how comfortable they think they would feel in these situations (plus one additional situation involving going to the beach). The response options range from 1 (very uncomfortable) to 4 (totally comfortable), and possible total scores range from 11 to 44.

The Hospital Anxiety and Depression Scale (HAD Scale) is a questionnaire designed to assess anxiety and depression in people with physical disorders (Zigmond and Snaith, 1983). A separate score is provided for anxiety and depression. Scores range from 0 to 21 and are categorised into three levels: 0-7=normal
range; 8-10=borderline range; 11-21=clinical range.

The Rosenberg Self-Esteem Scale (RSE Scale) measures self-esteem, or perceived self-worth, which is part of the wider construct of self-concept (Rosenberg, 1965). This is a validated questionnaire which has been previously employed in a wide range of psychological studies; previous scores from a sample of 2,294 adults aged between 18 and 65 years provide normative data. Scores range from 10 to 40 with low scores indicating high self-esteem. Normal population means are 35.01 (SD=4.78) for men and 34.52 (SD=4.91) for women.

Procedure

Full ethical approval to conduct the research was obtained. The amputee group was recruited by the Independent Limb Centre from where the amputees were receiving their prosthesis. Staff provided individuals fulfilling the inclusion criteria (i.e. lower limb amputees aged between 18-60 without life-threatening illness) with a letter inviting them to participate in the study and a consent form. Amputees who completed and returned a consent form were sent the first questionnaire pack approximately one month before they were due to take delivery of their prosthesis. The second questionnaire pack was sent approximately twelve weeks after they had taken delivery of their prosthesis, accompanied by a letter debriefing participants and thanking them for their participation. Participants who did not return the questionnaire pack after two weeks were sent a follow-up letter and another questionnaire pack, and a final reminder was made by telephone. One amputee failed to return the second questionnaire pack.

The normal population sample was recruited through an advertisement on the University of Southampton’s internal mail system. Students wishing to participate in the study were asked to reply to the email. These students were sent a consent form, questionnaire pack and addressed envelope via the internal mail system, pigeon holes or their home address (if stated). Consent forms and completed questionnaires were returned anonymously to the Health Psychology office. A random sub-sample of 25 of this group completed a second questionnaire pack after a twelve week interval. (Copies of the questionnaires developed in this study with scoring instructions and normative data can be obtained from the authors.)

Results

Participants’ scores were normally distributed and therefore parametric analyses could be carried out. The psychometric properties of the EEARB and Discomfort-EEARB were assessed using the data collected from the normal population sample. Analysis of internal consistency revealed excellent reliability for the Discomfort-EEARB, with a Cronbach’s alpha of .91, whereas the EEARB had only moderate

<table>
<thead>
<tr>
<th>EEARB Items</th>
<th>Factor 1 (Public places)</th>
<th>Factor 2 (Romantic partner)</th>
<th>Factor 3 (Buttocks, legs and feet)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taken a shower in a public place (e.g. a gym, sports centre)</td>
<td>.88</td>
<td>-.02</td>
<td>.02</td>
</tr>
<tr>
<td>Taken a shower or bath with or in front of a romantic partner</td>
<td>.87</td>
<td>-.03</td>
<td>.04</td>
</tr>
<tr>
<td>Used a public gym/sports centre</td>
<td>.76</td>
<td>.14</td>
<td>.09</td>
</tr>
<tr>
<td>Used a public swimming pool</td>
<td>.55</td>
<td>-.11</td>
<td>.02</td>
</tr>
<tr>
<td>Taken a shower or bath in front of a romantic partner</td>
<td>.02</td>
<td>.94</td>
<td>.07</td>
</tr>
<tr>
<td>Undressed in front of a romantic partner</td>
<td>.05</td>
<td>.94</td>
<td>.07</td>
</tr>
<tr>
<td>Worn tight trousers/leggings etc</td>
<td>.16</td>
<td>.01</td>
<td>.86</td>
</tr>
<tr>
<td>Worn open toe sandals</td>
<td>-.01</td>
<td>.15</td>
<td>.78</td>
</tr>
<tr>
<td>Worn a short skirt or pair of shorts</td>
<td>.12</td>
<td>-.07</td>
<td>.88</td>
</tr>
<tr>
<td>Walked about in front of people with bare legs, tights or stockings</td>
<td>-.02</td>
<td>.16</td>
<td>.76</td>
</tr>
</tbody>
</table>

Factor loadings >.40 are highlighted in bold face.
The effects of the appearance of the prosthesis

Table 2. Correlations among questionnaires in able-bodied control sample (n=101).

<table>
<thead>
<tr>
<th></th>
<th>EEARB</th>
<th>Discomfort EEARB</th>
<th>Self-esteem</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discomfort EEARB</td>
<td>.39**</td>
<td>-.38**</td>
<td>.63**</td>
<td>.55**</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>-.23*</td>
<td>-.31**</td>
<td>.51**</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>-.22*</td>
<td>-.28**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>-.30**</td>
<td>-.28**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

reliability, with a Cronbach’s alpha of .65. In order to determine whether the lower internal consistency of the EEARB was due to a multidimensional scale structure, principal component factor analysis with Varimax rotation was conducted on the ten items of the EEARB scale (Howitt and Cramer, 1997). This analysis confirmed a multidimensional scale structure, as 3 meaningful factors were extracted with Eigenvalues greater than 1.00 (see Table 1 for factor loadings). The first factor comprised the 4 items relating to revealing the body in a public place, the second factor related to having a romantic partner, and the final factor related to revealing the lower part of the body. Internal reliability was calculated for the three sub-scales created from the highest loading items on each factor. Cronbach’s alpha was .77 for factor 1, .65 for factor 2, and .86 for factor 3. This analysis suggests that the EEARB contains three distinct sub-scales, with moderate to excellent internal reliability.

Pearson’s Product Moment correlations indicated a test-retest reliability of 0.67 for the EEARB (p<.001), and 0.55 for the Discomfort-EEARB (p<.01), which was comparable to that of the Rosenberg Self-Esteem scale (r=.64, p<.001), and validated measures of anxiety (r=.49, p<.05) and depression (r=.63, p<.001). As expected, the EEARB and Discomfort-EEARB were moderately but significantly correlated with the measures of self-esteem, anxiety and depression (Table 2).

Table 3 compares the proportion of amputee and able-bodied participants who engaged in activities involving revealing the body during the previous three months. Before receiving a silicone cosmesis, the vast majority of amputees avoided revealing their lower limbs in public. Mean scores of amputees and able-bodied participants on the EEARB and Discomfort EEARB are shown in Figure 1. MANOVA confirmed a significant difference between the scores of amputees, able-bodied males and able-bodied females at Time 1 (Pillai’s Trace (5,214) =11.52, p<.001).

Table 3. Engagement in activities involving revealing the body in amputees, before (Time 1) and after (Time 2) receiving a silicone cosmesis, and in able-bodied controls.
Univariate tests for between subjects effects indicated a significant difference between the groups on the total score for the Discomfort-EEARB \((F(2,109)=31.7, p<.001)\), the lower body sub-scale of the EEARB \((F(2,109)=18.8, p<.001)\), anxiety \((F(2,109)=7.56, p<.001)\), depression \((F(2,109)=8.78, p<.001)\), and self-esteem \((F(2,109)=4.22, p<.05)\).

Post hoc Bonferroni tests indicated that amputees' scores differed from both able-bodied females' and males' scores on the Discomfort-EEARB \((p<.001)\), and on the lower body sub-scale of the EEARB \((p<.05)\). For anxiety, depression and self-esteem, it was found that amputees' scores differed from both able-bodied males' and females' scores \((p<.05)\), although able-bodied males and females' scores did not significantly differ.

Following receipt of the cosmesis there was a very marked increase in engagement by amputees in activities involving revealing the body, to levels only a little lower than in the able-bodied sample (see Table 3 and Figure 1). Paired t-tests confirmed that amputees' EEARB and Discomfort-EEARB scores increased significantly \((t(9)=-3.01, p<.05)\) and \((t(9)=-5.08, p<.01)\), respectively. Amputees' scores were reduced on the self-esteem, anxiety and depression scales at Time 2 (Fig. 2), although this decrease did not reach significance. In contrast, in the sub-group of able-bodied controls who completed the measures on two occasions, scores on the Discomfort-EEARB actually decreased slightly over a three-month period \((t(23)=2.69, p<.05)\), while scores on the other scales did not change significantly.

**Discussion**

The scales developed to measure engagement in activities revealing the body proved to be reliable and valid measures for use in the amputee population. They had similar psychometric properties to validated generic scales of self-esteem, anxiety and depression, and were more sensitive to the effects of receiving a silicone prosthesis. Discriminant validity was demonstrated by their ability to discriminate between amputees and able-bodied controls. Convergent validity was demonstrated by the modest but significant association between scores on these scales and on the generic measures of self-esteem, anxiety and depression. These findings are consistent with previous research showing that psychological adjustment problems, such as anxiety, depression and self-esteem, are related to amputees' perception of their body-image (Engstrom and Van de Ven, 1999). However, as the psychometric properties of the scales were assessed in an able-bodied sample, it would be desirable to confirm these properties in a larger amputee sample.

The two scales appear to serve complementary roles. Scores on the EEARB have the advantage of assessing actual behaviour, but are influenced partly by factors other than body-image (such as whether the respondent has a romantic partner, or would normally wear short skirts or use public sport facilities). The Discomfort-EEARB is not influenced by such factors, and provides a
measure of the social discomfort evoked by these activities. For example in this study, amputees' reported behaviour as measured by the EEARB, approached that of able-bodied participants at Time 2 but the Discomfort-EEARB scores revealed that amputees remained substantially less confident in undertaking activities involving revealing the body. Twelve weeks after taking delivery of a prosthesis with a silicone cover, there were significant increases in amputees' reported frequency of engaging in activities which involved revealing the body. Amputees' perceptions of how comfortable they thought they would feel when engaging in activities which involved revealing the body also significantly increased. These changes in behaviour and confidence provide some preliminary evidence that receiving a silicone cosmesis may enhance the psychological adjustment of some amputees. However, several aspects of the design make it impossible to generalise from these initial findings to the wider amputee population.

Firstly, it proved impossible in the time-frame of this study to recruit a case-control sample of amputees receiving a different prosthesis. Consequently, the possibility remains that receiving any new prosthesis might induce similar changes. Secondly, the amputees who received the silicone cosmesis were a sample who chose to privately purchase or were referred specially for a prosthesis with a silicone cover. As there was not a random sample of amputees with which to compare the base-line scores of the silicone recipients, it is impossible to determine whether or not these amputees' scores were representative of the amputee population as a whole. However, it is clear that the demographic characteristics of the sample were not typical; participants were mainly female, and were much younger than the typical amputee population. It may have been the case that individuals who choose to have a silicone limb are those who find the appearance of their NIS limbs particularly distressing, or who are most concerned about the appearance of their limb, and therefore are most likely to show an improvement following receipt of a silicone cosmesis. Thirdly, improvements in self-esteem, anxiety and depression were observed but did not reach statistical significance. This may have been due to the low power of the study to detect changes, owing to the small sample size. Finally, although this study showed improvement on all measures twelve weeks after taking delivery of a prosthesis with a silicone cover, it was not possible to carry out a longer-term follow-up. It is possible that such short-term improvements might have been due to factors such as expectations or financial outlay, and it is currently unknown whether this improvement would be sustained. These issues highlight the need for further research into the prevalence in the amputee population of significant psychological distress and behavioural limitation related to the appearance of the prosthesis, and larger, randomised controlled studies with long-term follow-up to determine whether distress can be reduced by various different prostheses.

In conclusion, this study validated two new scales to assess behaviour and confidence relating to revealing the body in a population of people with lower limb amputations. In a sample of amputees anticipating delivery of a prosthesis with a silicone cover, these scales revealed significant behavioural limitations and discomfort, associated with low self-esteem, anxiety and depression, when compared with an able-bodied control sample. Following delivery of this cosmesis, the amputees reported engaging in significantly more activities which involved revealing their body, and stated that they would feel more comfortable in situations which involved revealing the body. These findings indicate that the EEARB and Discomfort EEARB can provide clinicians and researchers with a sensitive and valid means of detecting and assessing behavioural limitations and distress associated with concern about the appearance of a prosthesis. As there has been limited previous research on the effect on patients' quality of life of the appearance of the prosthesis, these preliminary findings suggest that receiving a more realistic cosmesis may reduce behavioural restrictions and distress, which represents an important starting point for further investigation. While it has been argued that the desire for a silicone cosmesis may reflect the amputee's failure to accept and adjust to their limb loss, there is no published research showing that the choice of a realistic-appearing limb is associated with poor adjustment. There is consequently a clear need for larger surveys, case-control studies, and randomised controlled
trials in order to determine who might benefit from a cosmesis, and to compare the effects of different prostheses and cosmeses on behaviour and psychological adjustment.

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REFERENCES


