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Assessing Body Image in Patients with Systemic Sclerosis (Scleroderma): Validation of the Adapted Satisfaction With Appearance Scale

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Abstract

People with scleroderma often experience disfiguring appearance-related changes in socially visible and interpersonally salient areas. Although disfigurement can lead to body image dissatisfaction, this phenomenon has not been well investigated due to the lack of a disfigurement-specific measure. The Satisfaction With Appearance (SWAP) scale, previously developed in burn survivors, was adapted and administered to 254 participants with scleroderma to evaluate its psychometric integrity and its validity for use in a different medical population that experiences changes in appearance. Principal component analysis revealed two factors – Subjective Dissatisfaction and Perceived Social Impact —rather than the four found in burn victims. Excellent estimates of internal consistency and temporal stability and strong evidence for the reliability of the two-factor solution were found. The resulting factor structure in a scleroderma populations suggest that differing medical conditions may create alternate constellations of BID, reflects the need for body image researchers to assess psychometrics across medical populations and may have clinical implications for BID interventions.

Keywords

Body image; Scleroderma; Disfigurement; Social impact; Assessment

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Body image has been long studied in the context of physically healthy individuals and persons with eating disorders. Recent interest has extended to medical populations (Benrud-Larson, Heinberg, Boling, Reed, White, Wigley, et al., 2003) where appearance-related changes and disfigurements are readily visible and interpersonally salient (e.g. facial scars) and can pose significant challenges to the preservation of positive self-esteem and body image (Rumsey, 2002).

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Systemic sclerosis (scleroderma) is a progressive connective tissue disease that is associated with significant appearance-related changes. It is a relatively rare condition marked by inflammation, vascular insufficiency, and fibrosis. These processes result in disfiguring skin thickening, ischemic ulceration, and internal organ involvement (Wigley, 2002). The degree and course of the disease varies markedly by individuals and may include severe dysfunction of the skin, musculoskeletal system, and internal organs (e.g., lungs, heart). For patients with the more severe subtype of the disease, diffuse scleroderma, symmetrical and widespread thickening of the skin and relatively early internal organ involvement may occur leading to a poorer prognosis (Poole & Steen, 1991). In limited scleroderma (also known as CREST), skin thickening is generally limited to the face and hands and internal organ involvement may not occur for years or even decades after initial diagnosis (Poole et al., 1991). Scleroderma patients frequently experience skin discoloration and/or hardening, skin tightening around the mouth, finger lesions, and in some cases digit amputation. Thus, scleroderma often disfigures the most visible and interpersonally salient body parts (i.e., hands, mouth). Malcarne and colleagues (1999) found that skin thickening of the hand was associated with poorer psychosocial functioning and appearance self-esteem than changes at other sites. The degree of this distress may be significant. Indeed, scleroderma patients report greater body image dissatisfaction (BID) than those hospitalized for severe burn injuries (Benrud-Larson et al., 2003).

The lack of an appropriate instrument to assess body image has hampered the study of body image in scleroderma. Much of the basic research on the development and assessment of BID has grown out of the eating disorders literature and these measures generally assess the weight, shape and size components of body image (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). The basic assumption of these measures is that an individual's appearance is relatively normal. As a result, published norms are inapplicable to disfigured populations. One instrument, the Derriford Appearance Scale (Carr, Harris, & James, 2000) was developed for use on individuals undergoing plastic surgery for aesthetic reasons (e.g., rhinoplasty) or for those with congenital or acquired disfigurements. Although this measure has strong psychometrics, its length (59 items) and lack of site-specific dissatisfaction ratings make it less than ideal for use in certain medical populations. Recently, in order to better assess body image in disfigured burn populations, the Satisfaction With Appearance (SWAP) scale was developed (Lawrence et al., 1998).

The Satisfaction With Appearance (SWAP) scale was developed to assess body image in disfigured medical populations (Lawrence, Heinberg, Roca, Munster, Spence & Fauerbach, 1998), focusing on both subjective body image distress as well as the social impact of BID (e.g., avoidance). The SWAP showed excellent psychometric properties in burn patients and recent work supports its validity (Fauerbach, Heinberg, Lawrence, Bryant, Richter, & Spence, 2002;Lawrence et al., 1998). Original psychometric work on the SWAP demonstrated four subscales measuring Social Distress, Facial Features, Non-facial Features, and Perceived Social Impact (Lawrence et al., 1998).

Similar to changes caused by burn injuries, scleroderma leads to dramatic skin changes in interpersonally salient sites and contractures in the hands. However, unlike burns or congenital disfigurements which are relatively static, the body image changes in scleroderma vary and likely worsen over time. Thus the SWAP is hypothesized to be useful for the assessment of body image distress in this population. However, the vastly disparate etiology, presentation and prognosis for this disease, as compared to burns or other conditions that require appearance-altering surgery such as head/neck cancer, may contribute to a different type of distress or social impact of disfigurement. It is possible that a questionnaire developed for one population may not be suitable for another. Streiner (2003) asserted that investigators cannot sufficiently rely on published reports of reliability when using a scale in a new population. This caveat has also been reiterated in the body image literature (Thompson, 2004). Thus, we investigated the

factor structure and psychometric properties of the SWAP in a sample of patients with scleroderma who completed surveys over a five-year period in order to adapt its use in this population. It was hypothesized that patients with an appearance-altering disease may differ significantly in their pattern of responses compared to those with an appearance-altering injury. Further, we hypothesized that those with more severe disease involvement (diffuse subtype) would experience greater BID than those with less severe disease (limited subtype). We describe the factor structure of the Adapted SWAP (ASWAP), its reliability, its discriminant validity, its relationship with other measures of interest, and its normative properties in a sample with this disfiguring chronic illness.

Method

Participants

Study participants were recruited from all patients diagnosed with limited or diffuse scleroderma through the Johns Hopkins and University of Maryland Scleroderma Center between 1997 and 2002 as part of a larger longitudinal study examining psychosocial adjustment to scleroderma. For Time 1, participants were initially recruited in the clinic to participate in a larger longitudinal study of psychosocial adjustment among individuals with scleroderma. Once recruited, participants either immediately completed the survey in person (*N*=21) or took it home and returned it by mail (*N*=233). Informed consent was obtained by a research assistant for those participants surveyed in person or a signed consent form was returned along with the survey for participants who completed the questionnaires by mail. All surveys and consent procedures were reviewed and approved by Johns Hopkins University School of Medicine Internal Review Board. Time 2 participants (*N*=169) completed the questionnaires again approximately 18 months later. Similarly, the participants were contacted 18 months later for a Time 3 assessment. A subset of Time 3 individuals (*N*=66), who agreed to take part in a fourth supplemental survey to determine test-retest reliability, completed only the SWAP items, 4 months after completion of the third survey.

The Time 1 sample consisted of 254 participants. These participants were primarily Caucasian (75.5%) and female (85.5%). The majority, 65.7%, had limited disease, had at least a high school education (91.3%), and had a mean age of 52.8 years (*SD* = 12.9; range=27–81 years). This sample has been previously described (Benrud-Larson et al., 2002,2003). In the previously published study examining body image and depression (Benrud-Larson et al., 2003) only women participants and SWAP total scores were utilized; in the second published work on pain and depression, body image was not examined (Benrud-Larson et al., 2002). Because our earlier work did not explore the psychometric properties of the measurement of body image, the present study was conducted.

The majority of the original participants completed the Time 2 Survey (*N*=169, 66.5%) and the resulting sample had similar characteristics to the first. The participants at these two time-points were used for all analyses except those assessing stability. To determine test-retest reliability, 66 patients who completed Time 3 of the longitudinal survey and who agreed to complete a Time 4 supplemental survey were utilized. This group had similar characteristics to those at Time 1 and 2 (92% Caucasian, 92% female; 70% limited disease, all had at least a HS education; *M* age=54.0; *SD*=9.4; range=33–86). A definitive diagnosis using the American College of Rheumatology criteria for scleroderma (and its subtype) was made by the treating rheumatologist (BW or FW). All participants were being treated for their scleroderma during the course of the longitudinal study.

Measures

The Satisfaction With Appearance Scale (SWAP; Lawrence, et al. 1998) was developed to measure non-weight-related BID at multiple body sites and social discomfort related to appearance. On the SWAP, participants are asked to rate the degree to which each item accurately reflects their thoughts and feelings about their appearance since being injured. Ratings are made on a 7-point scale ranging from 1 (strongly disagree) to 7 (strongly agree). The total SWAP score is calculated by subtracting 1 from each item in order to anchor queries at 0 and then totaling items in subscales. Questions 4–11 are reverse scored and higher scores reflect greater dissatisfaction or distress (Lawrence et al., 1998).

The SWAP was first developed and tested on 165 burn victims (Lawrence et al., 1998), where the instrument showed good internal consistency (coefficient alpha=.87) and moderate test-retest reliability after two months (r=.59). A principal components analysis with varimax rotation suggested that 14 of the 15 items loaded on 1 of 4 scales: Social Distress, Facial Features, Non-facial Features, and Perceived Social Impact. The fifteenth item, “My appearance makes others feel uncomfortable,” was not included in the final version, because it did not load distinctly on any factor. This item was reintroduced for the present analyses of the ASWAP. ASWAP items that included the word “burn” were changed to “illness” but all other wording was identical to the original SWAP.

The Multidimensional Body-Self Relations Questionnaire - Appearance Orientation subscale (MBSRQ-AO; Brown, Cash, & Mikulka, 1990) is a multi-dimensional measure of attitudes toward the physical self including physical appearance, fitness and health. The 12-item Appearance Orientation subscale measures one type of cognitive-behavioral investment of appearance in self-esteem. High scorers place importance on looking attractive and engage in behaviors which manage or enhance their appearance. This subscale was used in this study to assess convergent validity. Further, it was included as part of the larger longitudinal study to examine the influence of appearance investment in adjusting to chronic illness. Because it was developed in non-medical populations, it was hypothesized that it would positively correlate with the ASWAP, but only to a moderate degree due to its emphasis on appearance investment rather than appearance satisfaction. In this scleroderma population, the internal consistency (coefficient alpha) for Time 1 was .87.

Body Image Avoidance Questionnaire (BIAQ; Rosen, Srebnik, Saltzberg, & Wendt, 1991) is a 19-item self-report questionnaire that was created to measure the behavioral dimension of body-image disturbance such as the avoidance of intimacy or wearing specific types of clothing to hide appearance (Rosen et al., 1991). It was selected to determine convergent validity. Since a number of items of the instrument are more relevant to weight/shape concerns, it was hypothesized to have a moderate positive correlation with the ASWAP. The internal consistency (coefficient alpha) was .82 for Time 1 and .87 for Time 2 in our sample.

The Beck Depression Inventory (BDI; Beck & Beamesderfer, 1974) was used to assess depressive symptoms. The 21-item BDI has been used extensively in studies of chronic illness and has been used in previous research with scleroderma patients (Benrud-Larson et al., 2002;Benrud-Larson et al., 2003). It was selected to discern whether the ASWAP mainly measured negative affect rather than body image. Depression and body image are known to have a moderate positive relationship (Stice & Agras, 1998;Thompson, et al., 1999). However, a very high positive correlation would suggest that the ASWAP is only a measure of psychological distress or negative affect. The internal consistency (coefficient alpha) of the BDI for both Time 1 and 2 was .90.

The Health Assessment Questionnaire (HAQ; Fries, Spitz, & Young, 1982) was modified for use in scleroderma (Steen & Medsger, Jr., 1997) and is widely used in this medical population

to assess physical function. A total score comprised of four of the eight subscales, Dressing and Grooming, Arising, Eating, and Walking, 8 items in total, was used in this study. Only these subscales were selected because of the likely greatest relevance for this disease population and to reduce subject burden in the longitudinal study. This measure was added to assess discriminant validity with the expectation of a moderate to low correlation. Amongst our scleroderma population, the internal consistency (coefficient alpha) of this questionnaire was . 90 for Survey 1 and .92 for Survey 2.

The McGill Pain Questionnaire (MPQ; Melzack, 1987) is a 15-item measure of the sensory and affective dimensions of pain with demonstrated reliability and validity in various populations. The MPQ was utilized for determining discriminant validity with a hypothesized low correlation. The internal consistency (coefficient alpha) was .90 and .89, at Times 1 and 2 respectively.

Results

A four-factor principal component analysis (PCA) with varimax rotation was initially preset to explore whether the original four-factor model was relevant for patients with scleroderma (Lawrence et al., 1998), first using Survey 1 data and then using Survey 2 data. Each PCA yielded only two factors with eigenvalues greater than 1, although 71.1% and 77.1% of the variance was accounted for. Items did not load in the hypothesized manner. Specifically, in the first PCA, dissatisfaction with hands, arms, and chest significantly loaded on two scales, while in the second, the dissatisfaction with legs and chest each loaded on different factors. Thus, the four-factor model was deemed inappropriate for this population.

Based on these results, a two-factor model was examined because of the differing satisfaction and social impact items and because these distinctions have been previously noted in the body image literature (Thompson, Roehrig, Cafri & Heinberg, 2005). Indeed, the two-factor model was originally hypothesized in the development of the SWAP, but the original exploratory analyses in the burn population yielded four interpretable factors (Lawrence et al., 1998). The most parsimonious 1-factor solution was theoretically rejected given the consistent finding of multidimensionality of body image within the literature across a number of populations (Thompson et al., 2005). PCAs on both administrations of the ASWAP yielded a consistent two-factor solution that met *a priori* requirements. Specifically, the two-factor solution accounted for greater than 50% of the variance (range 59.07%–73.66%), eigenvalues were greater than 1 for both subscales (2.3–7.4), visual inspection suggested two factors and every item loaded exclusively on the anticipated factors for both administrations (see Table 1). Factor 1 included items measuring dissatisfaction with various areas of the body and was labeled Subjective Dissatisfaction; factor 2 included items measuring discomfort with or avoidance of social situations and was labeled Perceived Social Impact.

Good internal consistency was found for each subscale across both time points (Table 1). All values of Cronbach's alpha were above .88 and results of the mean inter-item correlation for both subscales at each time point met or exceeded Clark and Watson's (1995) recommended criteria for measures with narrow constructs. Inter-factor correlations were moderate, an indication that the two factors tap different constructs.

Mean Perceived Social Impact was 11.58 (*SD*=6.75) at Time 1 and 13.46 (*SD*=9.00) at Time 2. Mean Subjective Dissatisfaction at Time 1 was 22.41 (*SD*=9.15) at Time 1 and 22.24 (*SD*=8.99) at Time 2. An independent sample t-test was conducted to see if there were differences in ASWAP scores based upon disease severity. As hypothesized, individuals with diffuse scleroderma (*n*=69) reported significantly greater Perceived Social Impact subscale scores (*M*=13.33; *SD*=7.38) than those with the less serious diffuse sub-type (*n*=159; *M*=10.70;

SD=6.18; *t* (1,226)=2.60; *p*<.01). Similarly, a trend was found for greater Subjective Dissatisfaction in patients with diffuse disease (*M*=24.30; *SD*=8.53) than those with the limited sub-type (*M*=21.75; *SD*=9.23; *t*(1,226)=1.94; *p*=.056).

Test-retest reliability was determined using data (*N*=66) collected from the third and fourth administrations of the ASWAP. The mean time-span between administrations was 20.6 weeks (*SD*=2.30). Test-retest (Intra-class correlation) for factor 1 was 0.78 and 0.72 for factor 2. In addition, a repeated measures one-way analysis of variance was conducted to assess whether significant temporal changes had occurred. Both Subjective Dissatisfaction (*F*(1,65)=.216 ; *p*>.10) and Perceived Social Impact (*F*(1,65)=1.26; *p*>.10) were not significant. Overall, the ASWAP subscales demonstrated good internal consistency, unidimensionality, and reasonable stability over 4 months.

The discriminant validity of the subscales (Table 2) was examined using partial correlations controlling for disease type (limited or diffuse) due to its differential effect on function, mood, and pain (Mayes, 1999). The results partially demonstrate the expected pattern of correlations. The strongest relationships are seen with one of the scales expected to demonstrate convergent validity, body image avoidance (*r*s ranging from 0.29–0.55). The moderate nature of the relationship likely reflects that the measure assesses avoidance in many weight and shape related domains that may or may not be relevant for individuals with scleroderma. Unexpectedly, the correlations with appearance orientation were quite low. Moderate correlations were demonstrated with the HAQ (*r*'s ranging from 0.33–0.43), a measure of scleroderma's impact on physical function and, as hypothesized, the lowest correlations were seen with pain (*r*'s ranging from 0.23–0.33). As expected, moderate correlations occurred with the BDI (*r*'s ranging from 0.40–0.57). However, the strength of the relationship indicates that the ASWAP is not just an instrument measuring negative affectivity.

Discussion

This study was designed to assess the psychometric properties and validity of the ASWAP on participants with scleroderma, a rheumatic and connective tissue disease in which individuals frequently experience visible and interpersonally salient disfigurements. The ASWAP showed excellent estimates of internal consistency and temporal stability, strong evidence for the reliability of a 2-factor solution, encouraging convergence with some measures thought to be addressing the same construct, and good correspondence with distinct but presumably related constructs. The results support the utility of the ASWAP and its two subscales for measuring body image in patients with scleroderma. Due to the obvious and sometimes dramatic nature of the symptoms of scleroderma it is common for those with the disease to experience distress regarding how they view themselves and/or to have concerns about how others may view them (Benrud-Larson et al., 2003). Unfortunately, research in this area, as in other areas of disfigurement due to physical conditions or surgical procedures, has been hampered by the lack of a psychometrically sound instrument for assessing body image.

The PCA of the ASWAP revealed a two-factor model that is internally consistent, stable and consistent across administrations. This model differed from the four-factor formulation developed for burn patients (Lawrence et al., 1998), an important finding that reinforces the need to examine psychometric properties in new patient groups, particularly in the early stages of a scale's development. Body image concerns experienced by those with disparate physical conditions likely differ and influence patients' response patterns. Burn victims tend to have highly focused, sudden injuries whereas patients with scleroderma tend to experience a range of skin conditions over a diffuse area of their body that can occur over months and years. Although burn injuries change and evolve over time, their location is relatively constant. In contrast, the waxing and waning nature of scleroderma may result in significant changes over

time on the extent, appearance and location of scleroderma-related appearance changes. Furthermore, the observed differences in factor structure may be at least partially attributable to sex differences in the patient groups. Burn victims are more likely to be male (73.3% of the sample compiled in the original validation of the SWAP was male; Lawrence et al., 1998), whereas scleroderma occurs most commonly in women (85.5% in the present sample). A long-term goal of future research in this area will be to collect sufficient data on various medical conditions to better determine whether psychometric differences are based on disease, gender, or their interaction, which would be critical in theory development.

Analysis of the ASWAP's discriminant validity findings suggests that the instrument is measuring a different construct than other body image instruments that were not originally designed for use in the medically disfigured. The low correlation between both subscales of the ASWAP and the MBSRQ-Appearance Orientation subscale was contrary to hypotheses. In this study, cognitive-behavioral investment in looking attractive and behaviorally managing one's appearance did not relate highly to a measure assessing body image concerns due to illness-related changes in individuals with scleroderma. This may be due to the fact that the MBSRQ-Appearance Orientation subscale measures motivational investment not the more problematic self-evaluative aspect (Cash, Melnyk & Hrabosky, 2004). In contrast, as expected, moderate correlations between the ASWAP and body image avoidance behaviors were found. The lack of a stronger relationship is likely due to utilizing an instrument that was developed for the weight/shape aspects of body image rather than disfigurement. Some items on this instrument are relevant whereas others may not be sensitive to body image in disfigured populations (e.g., wearing baggy, loose fitting clothing). The moderate correlation between the BDI and both subscales of the ASWAP indicates that mood and body image are measuring overlapping but different constructs, which has been widely observed (Thompson & Daniel, 1996). The relationship between subscales of the ASWAP and the modified HAQ is similar to previous research (Benrud-Larson et al., 2003) and likely represents the broad impact of scleroderma on both disfigurement and function. The significant correlations between the MPQ and the ASWAP indicate that a significant percentage of scleroderma patients who experience BID also experience pain (Benrud-Larson et al., 2002), which is frequent in the population. Pain may serve as a sensory cue, reminding patients of their disease and, in turn, their appearance changes.

The different factor structure seen in patients with scleroderma, as compared to burn survivors, suggests that these different medical conditions may present with different constellations of symptoms. However, other issues such as social anxiety and avoidance may be reported by individuals regardless of the type, severity or etiology of their appearance-related changes or differences. The different symptom assemblages may suggest clinical implications for interventions focused on improving body image and its social consequences. Because people with two distinct medical conditions produced different patterns of responses, future research will need to investigate the factors associated with such differential responses, including gender, etiology of disfigurement, nature of the onset of disfigurement, areas of the body affected, and illness prognosis. Further, research should examine what experiences are similar or universal. Thus, interventions for populations with disfiguring illnesses and injuries aimed at reducing body image concerns will probably need to include standard treatment strategies as well as be tailored to the needs of specific medical conditions.

The present study is limited by reliance upon mail-in surveys and the self-selection bias inherent in such methodology. In addition, as previously stated, the majority of respondents were women. Thus, it is unclear whether the results may be generalized to men with scleroderma. Further, interpretation of the results is limited by the attrition across time points. Sixty six percent of participants completed both Time 1 and Time 2 surveys. This is likely reasonable for a study relying upon a mail-in survey and utilizing participants with a chronic

progressive disease (e.g., those with worsening disease may have had difficulty completing questionnaires by hand, may have had worsening disability or may have died). However, response patterns and factor structure may be different among individuals with scleroderma who chose not to participate.

The study of BID in medical populations is in its infancy, thus research requires development of a psychometrically sound measure. In this early stage of development, such instruments need to be scrutinized carefully so as to maximize understanding of how the items and scales perform across populations. Use of the ASWAP and other measures of psychosocial functioning will facilitate an understanding of non-weight related body image and how it relates to other psychological sequelae, such as depression. With the development of reliable and valid measures and further understanding of the body image concerns of the medically disfigured, future analyses can use confirmatory factor analysis, to test conceptual models of body image distress.

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Table 1

Rotated (Varimax) Factor Loadings for the ASWAP

Item	Time 1 (*N*=254) Factor 1	Time 1 (*N*=254) Factor 2	Time 2 (*N*=169) Factor 1	Time 2 (*N*=169) Factor 2
Perceived Social Impact				
1. Because of changes in my appearance caused by my illness, I am uncomfortable in the presence of my family.	−.252	**.668**	.137	**.824**
2. Because of changes in my appearance caused by my illness, I am uncomfortable in the presence of friends.	−.144	**.736**	.144	**.860**
3. Because of changes in my appearance caused by my illness, I am uncomfortable in the presence of strangers.	−.220	**.836**	.245	**.887**
4. My appearance makes other people uncomfortable.	−.167	**.809**	.263	**.866**
13. Changes in my appearance have interfered with my relationships.	−.082	**.753**	.253	**.854**
14. I feel that my illness is unattractive to others.	−.185	**.750**	.220	**.797**
15. I don't think people would want to touch me.	−.098	**.784**	.179	**.852**
Subjective Dissatisfaction Scale				
5. I am satisfied with the appearance of my scalp.	**.735**	−.279	**.728**	.343
6. I am satisfied with the appearance of my face.	**.625**	−.114	**.612**	.205
7. I am satisfied with the appearance of my neck.	**.805**	−.252	**.795**	.284
8. I am satisfied with the appearance of my hands.	**.799**	−.103	**.740**	.195
9. I am satisfied with the appearance of my arms.	**.532**	−.245	**.547**	.142
10. I am satisfied with the appearance of my legs.	**.845**	−.110	**.812**	.238
11. I am satisfied with the appearance of my chest.	**.666**	−.094	**.726**	.760
12. I am satisfied with my overall appearance.	**.832**	−.109	**.804**	.205

Reliability Estimates for the ASWAP	Time 1 (*N*=254)	Time 2 (*N*=169)
Cronbach Alpha		
Behavioral-Social Impact	.89	.95
Subjective Dissatisfaction	.89	.88
Inter-factor Correlations	.47	.48

Table 2

Convergent and Discriminant Validity Estimates for the ASWAP

	Time 1 (*N*=254)		Time 2 (*N*=169)	
	Subjective Dissatisfaction	**Social Impact**	**Subjective Dissatisfaction**	**Social Impact**
Convergent Validity				
Body Image Avoidance	.29*	.55*	.47*	.40*
MBSRQ-Appearance Orientation subscale	.18*	.07	--	--
Divergent Validity				
Health Assessment Questionnaire	.33*	.42*	.43*	.34*
McGill Pain Questionnaire	.29*	.32*	.33*	.23*

* $p < .01$