

A psychosocial intervention for female adolescents recovering from
burns and other disfiguring conditions

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Abstract (212/250 words)

Objective: To assess the impact of an innovative psychosocial intervention for young women recovering from burns or other disfiguring conditions.

Methods: Attendees completed validated questionnaires before and after the weeklong retreat and again three months later. Questionnaires assessed various domains of psychosocial functioning and appearance concerns. Participants who completed both a pre and a one week post-test for at least one of the questionnaires at their first retreat were included in the analyses. T-test for pairs were used to assess the differences between scores at baseline and one week and between baseline and three-month follow up.

Results: 78 (87.6%) of 89 unique participants completed at least one questionnaire on the first and last day of the retreat, and 14 (15.7%) also completed a third questionnaire three months later. There were statistically significant improvements on five measures, suggesting an increase in self-esteem, hopefulness, quality of life, and satisfaction with appearance and a decrease in depression. In the subsample that completed questionnaires three months after the retreat, the patterns suggested sustained improvements.

Conclusions: For young women with disfiguring conditions, there were significant improvements on five psychosocial measures after attending the retreat. These findings suggest the effectiveness of the Angel Faces retreat in improving the quality of life of young women adjusting to disfiguring conditions.

Keywords: female, adolescent, burn survivor

Introduction:

According to Centers for Disease Control and Prevention, burn injuries are the tenth leading cause of death and the fourth leading cause of injuries among children 0-17 years of age in the US (Borse & Sleet, 2009). It is estimated that 486,000 individuals are treated for burn injuries annually in the US, and approximately 40,000 of these individuals require hospitalization due to the severity of their burn injury (National Hospital Ambulatory Medical Care Survey, 2011; National Inpatient Sample, 2010). Improvements in medical care for burn survivors have led to increasing rates of survival (Meyer et al., 2007; Sheridan, 2002), but given the trauma (Saxe et al., 2005) and disfigurement that accompany many burn injuries, there is a great need to attend to a patient's quality of life for longer periods post-burn (Meyer et al., 2007).

Although prior research suggests that the majority of child and adolescent burn survivors positively adapt throughout their recovery, studies have shown that approximately 15-20% of children who suffer from a burn injury develop significant psychosocial problems (Sheridan, 2002; Stoddard, Stroud, & Murphy, 1992). Burn survivors are at an increased risk of developing acute stress disorder, which can include both anxiety and dissociative symptoms within the first two weeks post-burn (Saxe et al., 2005). Significant psychosocial distress often persists beyond the first month of recovery as 13% (Maes, Mylle, Delmeire, & Altamura, 2000) to 28% (Madianos, Papaghelis, Ioannovich, & Dafni, 2001) of burn patients report depression at one year post-burn. Given the traumatizing nature of the actual burn incident, over the long term, burn

survivors are also at risk for developing Post Traumatic Stress Disorder (PTSD) (Meyer et al., 2007), with the severity of the resulting PTSD symptoms related to the survivor's health related quality of life as well as severity of depressive symptoms (Landolt, Buehlmann, Maag, & Schiestl, 2009; Stoddard et al., 1992).

Since burn injuries often result in scarring, amputations, and other visible differences, young burn survivors are also at risk for developing poor body image and/or low self-esteem (Pope, Solomons, Done, Cohn, & Possamai, 2007; Thombs, Lawrence, Magyar-Russell, Bresnick, & Fauerbach, 2008). Although some studies suggest that young burn survivors do not differ from their non-burned age mates in terms of body image disturbance (Pope et al., 2007), most studies have found that appearance concerns are more common among burn survivors (Van Loey & Van Son, 2003) since they are often subject to stares, avoidance, comments, or bullying during and after their recoveries (Lawrence, Rosenberg, & Fauerbach, 2007). Among youth with burn injuries, adolescent females were at increased risk for lower body self-esteem compared to males (Orr, Reznikoff, & Smith, 1989), and also reported more negative evaluations of how others see their appearance (Lawrence et al., 2007). Furthermore, prior research suggests a higher prevalence of depression among burn survivors who are female and/or adolescent at the time of their burns (Stoddard et al., 1992), and the social problems and poor social support that often accompany burn injuries have been shown to be common precipitants of depressive episodes (Orr et al., 1989). Since positive body image and self-esteem have been associated with better quality of life, mood, social comfort, and psychosocial adjustment and fewer feelings of stigmatization, (Fauerbach et al., 2000; Lawrence et al.,

2007; Pope et al., 2007), adolescents and females with burn injuries may be at especially high risk for negative outcomes in these areas.

In an effort to improve the quality of life of children with burn injuries, pediatric burn camps have grown greatly in popularity, and as of 2006, there were more than 40 camps for pediatric burn survivors in the United States (Rimmer et al., 2007). These camps are designed to provide children with burn injuries a safe and supportive environment to address psychosocial problems, experience success, enhance self-esteem, and engage in positive relationships, with the hope that these positive experiences will translate into more positive adaptations in the burn survivor's life outside of burn camp (Doctor, 1992; Rimmer et al., 2007). Although prior research suggests that these camps may improve self-esteem, there is limited research on whether these improvements are sustained after the camp or extend to promote outcomes in other domains of psychosocial functioning (Rimmer et al., 2007).

Although Angel Faces (<http://www.angelfaces.com/program-overview/>) has many similarities to traditional burn camps, it is also unique in several ways. The program, which was created by a woman who was severely scarred in an accident when she was a child, offers two different versions of a weeklong retreat that provide a comprehensive and holistic approach to healing for young women with burns and/or other disfiguring conditions. Now entering its 15th year, the Angel Faces Level 1 retreat is designed for young women 12-17 years of age to help them heal from the psychological impact of their traumas while also improving their body self-esteem and increasing their self-confidence and resilience. The Level 2 retreat is for older teens and young women in

their 20's. The retreats incorporate therapeutic approaches such as individual and group counseling sessions to help work through issues of trauma and loss and educational and strength-based activities like journaling and art therapy that are designed to promote emotional healing and growth. For most of the past ten years the program has used validated questionnaires to assess its impact on the young women who attended the retreat. The hypothesis of the current study is that the young women who attended the retreat would report immediate as well as sustained improvements on the questionnaires that assessed various areas of psychosocial functioning. The current paper reports on the changes in scores on these measures from the first to the last day of the retreat as well as exploratory analyses of whether the changes were sustained over a longer period of time.

Method

In 2009, 2010, and 2013-2017, participants were asked to complete questionnaires before and after the retreat and again three months later. The questionnaires used included the Rosenberg Self-Esteem Scale (RSES), Future Scale (AHS), Children's Dermatology Quality of Life Index (CDQLI), Strengths and Difficulties Questionnaire (SDQ), Social Anxiety Scale for Adolescents (SAS-A), Children's Depression Inventory (CDI), Satisfaction with Appearance Scale (SWAP), the Pediatric Symptom Checklist Youth Report (PSC-17-Y), and the Life Engagement Scale (LES). Participants who completed both a pre and a one week post-test for at least one of the questionnaires at their first retreat (some participants return for a second or third year) were included in the analyses. We used t-test for pairs to assess the differences between scores at baseline and

one week and between baseline and three-month follow up. The study was approved by the Partners Healthcare Institutional Review Board.

Measures

The Rosenberg Self Esteem Scale

The Rosenberg Self Esteem Scale (RSES) is a ten-item questionnaire that assesses self-worth by asking respondents about positive and negative feelings about themselves. Items are answered on a 4-point Likert scale ranging from 1=*Strongly Agree* to 4=*Strongly Disagree* (Rosenberg, 1965). Responses on the RSES have demonstrated a significant positive correlation ($r=.51$) with the Mental Component Summary of the SF-8 Health Survey) (Sinclair et al., 2010), which is an overall indicator of mental health, as well as a significant negative correlation with the Depression, Anxiety, and Stress (DASS-21) Depression ($r=-.62$), Anxiety ($r=-.47$), and Stress ($r=-.52$) subscales (Sinclair et al., 2010). The RSES has also demonstrated high internal reliability ($\alpha=.90$) (Sinclair et al., 2010) in a sample of 503 adults who were considered representative of the general US population.

The Future Scale (AHS)

The Future Scale, which often goes by the acronym AHS (Adult Hope Scale), is a 12-item questionnaire that contains an overall score for hope as well as two subscales assessing Agency (goal directed energy) and Pathway (planning to accomplish goals) (Snyder et al., 1991). Items are answered on an 8-point Likert-type scale ranging from 1=*Definitely False* to 8=*Definitely True* (Snyder et al., 1991). The AHS has shown high internal consistency for overall hope ($\alpha=.74-.84$), and for the Agency ($\alpha=.71-.76$) and

Pathways ($\alpha=.63-.80$) subscales in a sample of college students ($N=3920$) and individuals in psychological treatment ($N=206$) (Snyder et al., 1991). The AHS has also shown strong test-retest reliability after 3 weeks ($r=.85, p<.001$), 8 weeks ($r=.73, p<.001$), and 10 weeks ($r=.76-.r=.82, p<.001$) (Snyder et al., 1991). Additionally, the AHS has demonstrated a significant positive correlation with the Life Orientation Test, a measure of general positive outcomes expectations ($r=.50 -r=.60$) (Snyder et al., 1991) and with the Expectancy for Success Scale, which assesses respondents' expectations of reaching their goals ($r=.54-r=.55$) (Snyder et al., 1991).

The Social Anxiety Scale for Adolescents (SAS-A)

The Social Anxiety Scale for Adolescents (SAS-A) is a revised version of the Social Anxiety Scale for Children–Revised, with modified wording that makes the scale appropriate for self-report by adolescents (Inderbitzen-Nolan & Walters, 2000). The SAS-A consists of 18 items (with 4 filler items), which are answered on a 5-point Likert-type scale ranging from 1 = *Not at all* to 5=*All the time* with higher scores reflecting greater social anxiety. The SAS-A contains three subscales of Fear of Negative Evaluation (FNE) by others, Social Avoidance and Distress in New or unfamiliar situations (SAD-N), and Social Avoidance and Distress in the company of peers (SAD-General) (Inderbitzen-Nolan & Walters, 2000). Previous studies have replicated the three-factor structure as well as demonstrated high internal consistency ($\alpha=.76-.91$) in a sample of 250 adolescents in the 10th through 12th grade (La Greca & Lopez, 1998).

Children's Dermatology Quality of Life Index (CDQLI)

The Children's Dermatology Quality of Life Index (CDQLI) is a ten-item scale measuring the impact of skin conditions on quality of life for children ages 4 to 16 (Salek et al., 2013). The questions assess six areas of daily activities that include symptoms and feelings, leisure, school or holidays, personal relationships, sleep, and treatment (Salek et al., 2013). Items are answered on a 3-point Likert scale ranging from 0=*Not At All* to 3=*Very Much*, with higher scores representing greater impairment on quality of life (Lewis-Jones & Finlay, 1995). The CDQLI has demonstrated high internal consistency across six different samples (total N=408) of patients with a given skin disease ($\alpha=.82-.92$) (Salek et al., 2013).

Children's Depression Inventory

The Children's Depression Inventory (CDI) is a 27-item questionnaire used to measure depression in children ages 7 to 17 (Sun & Wang, 2015). Each item consists of three statements graded in order of increasing severity with scores ranging from 0 to 2. Respondents select the statement that characterizes their symptoms best during the past 2 weeks. The item scores are combined into a total depression score, ranging from 0 to 54, which are then converted into T-scores. A higher CDI score means a more depressed state. The CDI has demonstrated good to high internal consistency in a sample of 1,043 children ages 8-18 with chronic pain for the total score ($\alpha=.88$), negative mood subscale ($\alpha=.71$), interpersonal problems subscale ($\alpha=.54$), ineffectiveness subscale ($\alpha=.60$), anhedonia subscale ($\alpha=.67$), and negative self-esteem subscale ($\alpha=.62$) (Logan et al., 2013).

Strengths and Difficulties Questionnaire

The Strengths and Difficulties Questionnaire (SDQ) is a 25-item scale that consists of five subscales that assess Emotional problems, Conduct problems, Hyperactivity, Peer problems, and Prosocial behavior (Bourdon, Goodman, Rae, Simpson, & Koretz, 2005). The questionnaire assesses behavior in the past six months, and responses are scored on a 3-point Likert scale ranging from 0=*Not True* to 2=*Certainly True*. In a sample of 9,878 parent reports of children ages 4-17, the SDQ has demonstrated good internal consistency for Total Difficulties ($\alpha=.83$) and Impairment scores ($\alpha=.80$) as well as fair consistency for peer problems ($\alpha=.46$) (Bourdon et al., 2005).

Satisfaction with Appearance Scale

The Satisfaction with Appearance Score (SWAP) is a 14-item questionnaire that measures satisfaction with appearance on a subjective and social-behavioral level. Participants respond to how strongly they agree with each item on a seven-point Likert scale ranging from 1=*strongly disagree* to 7=*strongly agree*, with higher scores indicating decreased satisfaction with appearance (Lawrence et al., 1998). To calculate the SWAP total score, 1 is subtracted from each item, and then the item scores are summed to create a range from 0-84 (Mills et al., 2015). Questions 4-11 are reversed scored. The SWAP has demonstrated high internal consistency ($\alpha=.87$) and good test-retest reliability ($r=.59$) in a sample of 165 adult burn patients (Lawrence et al., 1998).

Pediatric Symptom Checklist-17-Y

The Pediatric Symptom Checklist is a widely used brief measure of overall psychosocial functioning, and both the 17-item versions of the parent (Murphy et al., 2016) and youth-report (Bergmann, Lucke, Nguyen, Jellinek, & Murphy; Montaña, Mahrer, Nager, Claudius, & Gold, 2011) have been validated. The current study used the youth self-report version of the 17-item Pediatric Symptom Checklist (PSC-17-Y). The PSC-17-Y asks young people to rate the frequency of each symptom listed on a 3-point Likert scale with the options of 0=*never*, 1=*sometimes*, 2=*often*, and the weighted scores are summed to create a total score ranging from 0-34. Total scores are recoded dichotomously to indicate overall mental health risk (or lack thereof) based on a cutoff score of 15 or higher on the global scale. The PSC-17-Y also provides total and categorical scores on three subscales for attention, internalizing, and externalizing problems. Each subscale includes 5 or 7 items that are also dichotomized to indicate mental health risk based on validated cut-off scores. Each subscale of the PSC-Y has demonstrated strong internal consistency (internalizing ($\alpha=.76$), externalizing ($\alpha=.73$), attention ($\alpha=.69$)) (Montaña et al., 2011). The optimal cut-off for the PSC-Attention Subscale (PSC-AS) and PSC-Externalizing Subscale (PSC-EX) is 7, and the optimal cut-off for the PSC-Internalizing Subscale (PSC-IS) is 5 (Gardner et al., 1999).

Life Engagement Scale

The Life Engagement Scale (LES) is a 10-item questionnaire that assesses whether an individual's worries about their appearance hold back their engagement in activities across several domains (social, recreational, educational) over the previous two weeks. Participants rate each item on a 4-point scale of 1=*hasn't stopped me at all to*

4=*stopped me all the time* with higher scores indicating decreased life engagement (Diedrichs et al., 2015). The Life Engagement Scale has demonstrated good internal consistency among parents ($\alpha=.88$) and adolescents ($\alpha=.92$) in a sample of 235 parent-child dyads (Diedrichs et al., 2016).

Intervention

The Angel Faces retreat is a six-day residential program that is located at either a retreat center or private vacation home complex. Although the specific content of the program slightly varies from year to year, the core program has remained consistent over the life of the program. The retreat incorporates daily yoga, art therapy, psychoeducation with licensed psychologists on topics such as trauma and loss, group sessions on how to cope with the difficulties associated with disfigurement such as teasing and staring, and one or two individual sessions with mental health professionals as needed. Additional activities include instruction for applying corrective cosmetics and massage therapy. The purpose of these activities is to help the participants improve their self-image and self-confidence while working through issues they may identify with in regard to trauma and disfigurement in a supportive environment.

Results

Sample Characteristics

In the seven years of data collection from 2009-2010 and 2013-2017, 89 young women attended the Level 1 Retreat, 23 of them returning for multiple retreats. Of the unique individuals, 78 (87.6%) completed at least one questionnaire on the first and last

day of the retreat, and 19 (21.3%) also completed at least one additional questionnaire three months after the retreat.

The average age of the 78 participants who completed at least one questionnaire before and after the retreat was 15.8 years. Approximately half of the participants were Caucasian (52.6%), 25.6% were Hispanic, 12.8% were African American, and 9.0% identified as other. Of these 78 individuals, 10 (12.8%) had a difference in appearance that was caused by a congenital defect. All remaining individuals had a burn injury or other type of trauma: 5 (7.3%) of them were injured at less than one year of age, 20 (29.4%) between the ages of 1-3, 25 (36.8%) between the ages 4-11, and 18 (26.5%) between the ages of 12-17. Almost all individuals whose disfigurement was caused by trauma was specifically due to a burn injury (95.6%). There was a wide range of burn injury severity as indicated by an individual's Total Body Surface Area (TBSA), which is the partial or complete destruction of skin caused by some form of energy. Among those who had documentation of their TBSA (N=64), 9 (14.1%) had a TBSA of 10-24%, 27 (34.6%) had a TBSA of 25-49%, 12 (18.8%) had a TBSA of 50-74%, and 16 (25.0%) had a TBSA of 75-95%.

Pre & Post Retreat Questionnaires

Different combinations of questionnaires were used each year due to changes in the focus of each year's retreat, the preferences of the psychologists running the intervention that year, and feedback from respondents. For the AHS and the Rosenberg scale, a higher score indicates better adjustment, whereas lower scores for the CDQLI, SDQ, CDI, SWAP, SAS-A, PSC-17-Y, and the LES reflect a more positive outcome.

As shown in Table 1, the young women who attended the retreat showed improvement on all nine measures, with the differences on five of them reaching statistical significance (with exception to the PSC Internalizing Subscale that had a non-significant increase from T1 to T2). Specifically, both the Rosenberg and the AHS scores showed significant increases in mean scores ($\Delta M=2.0$, $SD=4.8$, $p<.001$; $\Delta M=3.1$, $SD=6.8$, $p<.001$, respectively), and scores on the CDQLI ($\Delta M=3.2$, $SD=4.4$, $p<.001$), CDI-1 ($\Delta M=2.0$, $SD=3.1$, $p<.01$), and SWAP ($\Delta M=4.8$, $SD=5.1$, $p<.01$) significantly decreased from before to after the retreat.

As shown in Table 2, a subsample ($N=14$) of participants with pre and post tests also completed at least one questionnaire three months after the retreat. Although the sample for these analyses is small, improvements in quality of life on the CDQLI ($\Delta M=3.7$, $SD=3.8$), were significantly greater three months after the retreat than they had been on the first day of the retreat as well as lower (but not significantly so) than they had been at the end of the retreat. The SDQ and the Future Scale showed the same pattern of improvement from Time 1 to Time 2 to Time 3, but these changes failed to reach statistical significance. On the CDI-1, the scores at Time 3 were lower than they had been at Time 1 (although not lower than they had been at Time 2). The Rosenberg Self Esteem scale was the only scale to have the score at Time 3 that was significantly worse than it had been at the end of the retreat at Time 2 ($\Delta M=7.9$, $SD=11.8$).

Discussion

The current study suggests that the Angel Faces Level 1 retreat is associated with a measurable and significant positive impact on several different dimensions of

psychosocial well-being for adolescent girls recovering from disfiguring injuries from burns and other trauma. Given the increasing awareness of the importance of psychological as well as physical well being as a goal for recovery in the treatment of burned or otherwise traumatized individuals, the results of the current study fill a significant gap in the existing literature, suggesting that retreats such as Angel Faces have the potential to produce an positive impact on young women adapting to burns and other trauma in the longer term recovery period.

Although individuals with burn injuries are at an increased risk for psychosocial dysfunction, body image dissatisfaction, and low self-esteem (Pope et al., 2007; Sheridan, 2002; Stoddard et al., 1992), the current study suggests that intensive, comprehensive programs like the Angel Faces retreat can mitigate these risks over the short term.

Although the subsample that completed questionnaires three months after the retreat was too small to generate strong conclusions, the patterns did suggest that programs like Angel Faces could impact longer-term outcomes as well.

There are a number of limitations to this study. Since the Angel Faces retreat only includes young adolescent women who experienced burns and other trauma, the therapeutic activities that were associated with benefits in young adolescent women may not generalize to other subpopulations of individuals with burn injuries. In addition, the relatively low response rate for the three month follow up assessments demonstrates the need of additional efforts to increase participation in order to assess whether the benefits of attending the retreat persist several months after it is over.

Additional research is warranted, and future studies could assess whether certain aspects of the Angel Face program were more effective than others. Administering additional questionnaires to assess various aspects of the retreat could help inform whether certain activities had a greater therapeutic benefit, which would serve to make the current program as well as other retreats even stronger. Additionally, identifying ways in which the program could enhance existing methods for post-retreat support could greatly aid these young women in their recovery. Specifically, discovering means to continue the social support network that was developed while at the retreat or continuing education on how to translate certain skills into their everyday lives could greatly extend the impact of the Angel Faces retreat.

In conclusion, the Angel Faces retreat was associated with a measurable and significant positive immediate impact on several different dimensions of psychosocial well-being for adolescent girls and young women recovering from disfiguring injuries from burns and other trauma. The results of this study demonstrate the importance of retreats specifically designed for burn survivors and their potential to greatly improve quality of life post-burn.

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Table 1. Mean scores on outcome measures at the beginning and end of the retreat

	Intake Score Mean (SD)	Time 2 Score Mean (SD)	Change T2-T1 Mean (SD)
ROSENBERG (N=77)	20.8 (5.2)	22.8 (5.2)	2.0 (4.8) ***

FUTURE (N=74)	50.7 (7.6)	53.8 (8.0)	3.1 (6.8) ***
CDQLI (N=55)	6.88 (4.8)	3.7 (4.1)	3.2 (4.4) ***
SDQ (N=33)	25.7 (5.8)	25.1 (5.1)	.5 (4.6)
CDI (N=29)	6.9 (6.2)	4.9 (6.0)	2.0 (3.1)**
SWAP (N=12)	30.9 (16.1)	26.1 (15.1)	4.8 (5.1)**
SAS-A (N=12)	46.4 (13.7)	43.3 (15.4)	3.1 (5.5)
PSC-17-Y (N=12)	11.3 (4.9)	10.8 (3.9)	.5 (2.8)
PSC-17-Y Att (N=12)	4.8 (2.5)	4.6 (1.9)	.2 (1.9)
PSC-17-Y Int (N=12)	3.7 (1.8)	3.8 (1.4)	.1 (1.1)
PSC-17-Y Ext (N=12)	2.9 (2.2)	2.5 (2.1)	.4 (1.2)
LES (N=12)	15.0 (5.3)	14.0 (6.6)	1.0 (2.6)

* p<.05 **p<.01 ***p<.001

Table 2. Mean scores on outcome measures at the beginning, end of the retreat, and three months after the retreat

	Intake score Mean (SD)	Time 2 Score Mean (SD)	Time 3 Score Mean (SD)	Change T3-T2	Change T3-T1
ROSENBERG (N=14)	20.1 (5.8)	22.1 (5.5)	14.2 (11.3)	7.9 (11.8)*	5.9 (10.1)
FUTURE (N=13)	50.3 (8.2)	52.8 (7.4)	53.6 (7.4)	.83 (6.8)	4.0 (7.6)
CDQLI (N=13)	7.6 (5.0)	5.1 (4.4)	3.9 (4.7)	1.2 (3.2)	3.7 (3.8)**
SDQ (N=6)	24.5 (4.7)	23.7 (3.4)	23.0 (3.1)	.7 (3.8)	1.5 (6.1)
CDI (N=5)	2.6 (2.7)	1.4 (2.0)	1.8 (1.6)	.4 (3.1)	.8 (3.3)

* p<.05 **p<.01