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Long-Term Social Reintegration Outcomes for Burn Survivors With and Without Peer Support Attendance: A Life Impact Burn Recovery Evaluation (LIBRE) Study

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Abstract

Objective: To examine differences in long-term social reintegration outcomes for burn survivors with and without peer support attendance.

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Design: Cross-sectional survey.

Setting: Community-dwelling burn survivors.

Participants: Burn survivors (N = 601) aged 18 years with injuries to 5% total body surface area (TBSA) or burns to critical areas (hands, feet, face, or genitals).

Interventions: Not applicable.

Main Outcome Measures: The Life Impact Burn Recovery Evaluation Profile was used to examine the following previously validated 6 scale scores of social participation: Family and Friends, Social Interactions, Social Activities, Work and Employment, Romantic Relationships, and Sexual Relationships.

Results: Burn support group attendance was reported by 330 (55%) of 596 respondents who responded to this item. Attendees had larger burn size ($43.4\% \pm 23.6\%$ vs $36.8\% \pm 23.4\%$ TBSA burned, $P < .01$) and were more likely to be >10 years from injury (50% vs 42.5%, $P < .01$). Survivors who attended at least 1 support group scored significantly higher on 3 of the scales: Social Interactions ($P = .01$), Social Activities ($P = .04$), and Work and Employment ($P = .05$). In adjusted analyses, peer support attendance was associated with increased scores on the Social Interactions scale, increasing scores by 17% of an SD (95% confidence interval, 1%–33%; $P = .04$).

Conclusions: Burn survivors who reported peer support attendance had better social interaction scores than those who did not. This is the first reported association between peer support group attendance and improvements in community reintegration in burn survivors. This cross-sectional study prompts further exploration into the potential benefits of peer support groups on burn recovery with future intervention studies.

Keywords

Burns; Community integration; Rehabilitation; Social support

Reentry into society after burn injury can be a formidable task for many survivors. Physical challenges such as persistent pain, scars, amputations, and mobility restrictions are issues burn survivors face as they attempt to redefine themselves. Psychosocial issues also challenge burn recovery. Depression and posttraumatic stress disorder (PTSD) occur frequently, with PTSD being reported in 15% to 45% of burn survivors, more than 3 to 8 times higher than in the general population.^{1,2} Additionally, although less well documented, a significant number of burn survivors experience emotional distress, anxiety, insomnia, and body image problems.²⁻⁴ These conditions can be lifelong disabilities for survivors and can be associated with loss of their peer groups, unemployment, and social discomfort, leading to isolation.^{5,6}

Low perceived social support has been repeatedly associated with maladjustment after burn injury,^{5,7} and traditional psychological assistance or peer support can be instrumental in easing the transition of survivors back into their communities. Unlike traditional psychotherapy, peer support offers experiential knowledge and a social network of other burn survivors.⁸ Wisely et al⁹ found that among two thirds of patients found to have

psychological distress after burn injury, most of their needs could be met by hospital staff or peer supporters. By providing positive role models, peer supporters can help survivors gain a sense of hope and optimism for the future.^{8,10-13}

Peer support has a long legacy of documented success among individuals afflicted with a variety of illnesses. It has led to better coping and disease management in diabetes¹⁴; improvement in internalized stigma, self-esteem, self-efficacy, community activism, and autonomy in those with psychiatric illness¹⁵; greater ability to transcend their own boundaries and do things they previously thought not possible in individuals with multiple sclerosis¹⁶; ameliorated PTSD symptoms in war veterans¹⁷; and has helped mitigate the odds of developing depression after a traumatic injury.¹⁸

Studies assessing the benefits of peer support for burn survivors are more scarce, but evidence suggests that peer support is overwhelmingly viewed as positive by burn survivors. In a study by Badger and Royse,¹¹ survivors ranked the helpfulness of peer support 9.29 out of 10. Similar results were found by Sproul et al,¹³ who reported that 61% of the 117 survivors surveyed found “talking with another burn survivor” to be important. Further, Sproul described higher functioning on psychosocial assessment scales among peer support participants compared with those who did not participate. Badger and Royse^{11,12} reported higher functioning in survivors receiving support on several scales including Social Comfort and Life Satisfaction, and subscales of the Quality of Life scale (interpersonal relationships, affect, and sexuality). Both studies recruited subjects throughout the United States; however, their sample sizes were substantially smaller than the current study (117 and 98, respectively).

In this article, we sought to determine the associations of peer group attendance with the societal reintegration of a large group of burn survivors drawn from the United States and Canada using field test data from a new instrument developed to assess community reintegration in burn survivors, the Life Impact Burn Recovery Evaluation (LIBRE) Profile.

Methods

Study design and participants

This is a secondary analysis of a cross-sectional survey study of adult burn survivors. The data were collected as part of the field testing of the LIBRE Profile. Community-dwelling burn survivors were recruited between October 2014 and December 2015 through peer support groups, social media, burn clinics, the Phoenix Society for Burn Survivors, and the 2014 and 2015 Phoenix World Burn Congresses. Survivors aged 18 years with injuries to 5% total body surface area (TBSA) or burns to critical areas (hands, feet, face, or genitals) and who had not previously participated in earlier phases of the LIBRE study were included. If eligible, participants were asked further questions regarding work and employment, romantic relationships, and sexual relationships to determine the applicability of certain items in the LIBRE questionnaire.

Outcome measure

After successful completion of a screening module, participants were administered the LIBRE-192, which contains 192 items used for field testing of the LIBRE Profile that examine several areas of community participation after burn injury.¹⁹⁻²¹ The development of the 126-item LIBRE Profile from the LIBRE-192 has been described previously.¹⁹ Participants completed the LIBRE-192 in person, over the phone, or online. Individual items within each scale were coded on a 5-point Likert scale (1—5), with higher scores denoting better outcomes. Specific items were reverse-coded as necessary. The final 126-item LIBRE Profile was previously validated using exploratory and confirmatory factor analyses and contains 6 scales that examine the following domains of social reintegration: Family and Friends, Social Interactions, Social Activities, Work and Employment, Romantic Relationships, and Sexual Relationships.¹⁹ Scale scores were standardized to a mean of 50 and SD of 10.

Identifying peer support attendance

Two questions in the screening module addressed peer support. Support group attendance was determined by an affirmative response to the question, “Have you participated in a burn survivor peer support group?” The survivor was then asked the name or names of the support group(s) attended. Responses included hospital support groups, other peer support groups, regional support groups, multiday programming (such as burn camp and Phoenix Society World Burn Congress), Phoenix Survivors Offering Assistance in Recovery (SOAR) support, and other online support. The American Burn Association’s region classification was used to designate survivors’ geographic region of residence. Burn size was self-reported by the survivor; if a range was indicated, the middle of the range was used for analysis.

Statistical analysis

Demographic variables examined included age at time of survey, sex, race/ethnicity, and marital status. Clinical variables included TBSA burned, presence of burns to critical areas, and time since burn injury. These characteristics were compared between peer support participants and nonparticipants using chi-square tests, with statistical significance defined according to an alpha level of .05. Scores on individual items contributing to the 6 scales were compared between groups using analysis of variance. Multivariable linear regression models adjusting for significant demographic and clinical variables including sex, TBSA, and time since burn injury were constructed to evaluate the associations between peer support participation and LIBRE Profile scale scores. Statistical analysis was performed with SPSS version 20.^a The LIBRE study was approved by the Institutional Review Board of Boston University. The University of Iowa granted a waiver of institutional board review for the present analyses.

Results

The LIBRE-192 assessment was completed by 601 burn survivors. Data for peer support group participation were missing for 5 participants, who were excluded from all further analyses. Of the remaining 596 participants, most were white (463, 77.7%) followed by African American (56, 9.4%), Hispanic (40, 6.7%), and other race/ethnicities (33, 5.5%)

(table 1). The mean age of study participants was 40.5 ± 15.4 years; slightly more than half of participants were women (326, 54.7%), and slightly less than half were married (268, 45%). Approximately 40% had a bachelor's degree or higher (249, 41.8%), and over one half were currently employed (321, 53.9%). More than three quarters reported burns to critical areas (484, 81.2%).

Slightly over one half (330, 55%) of those in the study reported participating in peer support. Of these, 314 (95%) identified the support group or groups they attended (appendix 1). The subjects were distributed across the United States with some representation from Canada. Compared with participants who did not report receiving peer support, those who did report using peer support had a larger mean burn size ($43.4\% \pm 23.6\%$ vs $36.8\% \pm 23.4\%$ TBSA, $P < .01$) and tended to be further out in time from their burn injury (50% vs 42.5% >10y from injury, $P < .01$). There were no other statistically significant demographic differences between support group attendees and nonattendees (see table 1).

Peer support group attendance was associated with higher scores denoting better outcomes on 3 of the 6 scales: Social Interactions ($P = .01$), Social Activities ($P = .04$), and Work and Employment ($P = .05$) (table 2). After adjustment for sex, TBSA, and time since burn injury, the association remained statistically significant for the Social Interactions scale ($\beta = 1.7$; 95% confidence interval, .10—3.30; $P = .04$) (table 3).

Examination of scores on specific items in the Social Interactions scale showed that survivors attending peer support groups reported higher scores more frequently on several survey items. The items with the largest differences were those relating to making friends, dressing to avoid stares, and going to community events (table 4).

Discussion

This cross-sectional study revealed that those who reported attendance at a peer support group experienced better recovery for several social outcomes compared with their nonattending peers. In particular, attendees reported fewer restrictions in participating in social activities, relating and maintaining friendships, and dealing with strangers compared with burn survivors who reported no peer group exposure. This study extends the findings of previous qualitative studies and adds to the growing body of evidence that burn survivor peer support plays an essential and measurable role in successful recovery.^{8,10-13,22}

The process of burn recovery can be long and arduous. Although survivors differ in their needs for support, studies estimate that 24% to 56% of survivors seek some form of psychosocial help during their burn recovery, and of these, 38% to 63% have unmet psychosocial needs.^{23,24} Moreover, the recovery process can be fraught with gains and setbacks based on individual coping styles, support, environmental factors, and the severity of the injury.^{5,7,25,26} We see this in the significantly greater proportion of peer support attendees who sustained larger TBSA burns and tended to be further out from their injury. Although this may represent a sampling error, it also suggests that the struggles this group faces are unique and substantial, and alternative methods used during recovery may not have provided the more personal and individual benefits that may have been gained through

peer support. This is a promising indicator that earlier resource education using the LIBRE tool may help facilitate a more tailored, individualized, and beneficial approach for each survivor's unique road to recovery. As the focus shifts from one of survival to social reintegration, survivors need to reestablish their role in the family, the workplace, and the community. Inadequate adaptation may lead to loss of peer groups, marital strain, and/or unemployment.²⁷

Burn survivor peer counselors have shown success in helping with the recovery effort in qualitative studies,¹¹⁻¹³ but few quantitative studies have been completed.²² Two studies and now the current one provide evidence of the reintegration and health outcome benefits associated with peer support for burn survivors. Badger and Royse,¹² using the Perceived Value of Peer Support Scale, showed that high scorers experienced greater improvement in multiple areas of healthy functioning including social comfort, interpersonal relations, life satisfaction, and sexuality. Sproul¹³ showed that peer support was viewed as very important for burn survivor recovery by most of the 117 survivors surveyed, and also demonstrated more positive scores on Snyder's State Hope Scale.²⁸

The current study extends the evidence of the vital role that peer support can play in rehabilitation of burn survivors. Engagement in recreation and leisure activities is an important component of successful adjustment.⁵ In the current study, peer support attendees reported more freedom to participate in social activities. In particular, they had higher scores on items dealing with comfort around strangers, dressing to avoid stares, and avoidance of activities that might call attention to burns. By providing role models and a healthy set of relationship skills, peer support can offer emotional, instrumental (tangible goods or assistance with tasks), and instructional (feedback and guidance) assistance to help survivors better navigate daily encounters and reestablish relationships.^{8,11}

Study limitations

There are several limitations to this study. First, while the study reports associations between support group attendance and perceived gains in reintegration, causal relationships cannot be asserted. Those who chose to attend peer support groups may represent a self-selected group of individuals with attributes contributing to better adjustment and positive growth. Second, the peer support attendance group sustained significantly larger TBSA burn injuries and tended to be farther out from their injuries. These results may represent a sampling error and a group that has had a longer time to trial different support and coping styles that may improve adjustment, therefore exhibiting a more positive outlook and personal growth before peer support attendance. Third, recruitment from groups such as SOAR and the World Burn Congress may have further contributed to this bias. However, attempts were made to diversify the study sample using various recruitment methods at multiple clinical sites and outpatient clinics throughout the United States and Canada, mitigating this potential effect so that the groups were fairly heterogeneous. Evidence of this is the fairly equal number of participants from each region in the United States, and 26% of participants reporting Phoenix Society programs such as SOAR, Phoenix World Burn Congress, or Phoenix online chat as the support group attended. Lastly, support group attendance was assessed only by 1 question that required a yes or no response and was left open to variable

interpretation by the respondent. We were thus unable to investigate the impact of timing or type of peer support, which could theoretically range from a single visit to lifelong involvement. Moreover, burn survivors who interpreted the question literally as “peer support group attendance” and responded negatively to the question despite involvement with other peer support mechanisms may have influenced the results. This would, however, tend to bias results toward the null hypothesis with results reported to be somewhat conservative. Despite these limitations, this study is the largest and most comprehensive examination to date of the impact of peer support on the process of community reintegration in burn survivors.

While the causal implications of our study are limited, it does provide suggestions for future research. First, an analysis of the factors that are unaffected by support group attendance can help guide future modifications in survivor assistance programs. For instance, the lack of improvement in the Family and Friends domain may provide an area for more study to determine what factors are involved here and the impact of active family or peer involvement in support on the recovery of the survivor. Second, when is it important to engage survivors in peer support, and how do centers bridge the gap in their needs after discharge? Third, do differing types of peer support such as individual, formal group, or informal peer support have different impacts on outcomes? Lastly, what new avenues and approaches can we take to refer and recruit burn survivors into peer support? Future prospective studies are needed with peer support—based interventions designed to examine outcomes to establish causal relationships with social integration. With the massive growth in electronic communication come many opportunities to reach out to more burn survivors. Further research into these innovative outreach approaches is warranted.

Conclusions

This study provides empirical evidence of the important role peer support plays in meeting the needs of burn survivors and facilitating their successful reintegration into society. These findings support the establishment and tailoring of peer support programs that can effectively meet the needs of burn patients and their families.

Supplier

a. SPSS version 20; IBM Corp.

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Appendix 1

Peer Support Group Categories (n)

Hospital peer support group (104)

Other peer support groups (58)

SOAR (35)

Phoenix Society (30)

Peer supporters (26)

Burn camps/retreats (21)

Online/social media (13)

Multiple peer support groups (11)

World Burn Congress (7)

“Finger Lakes” (6)

Unknown (7)

Peer Support Group Category Descriptions

Hospital peer support group: Peer support groups with a direct affiliation to a hospital or burn center

Peer support group: Peer support groups not affiliated with a hospital

Online/social media: Phoenix online, Facebook, and other online resources

Peer supporters: Includes burn camp peer supporters and counselors, burn center peer supporters, and SOAR peer supporters/coordinators

Multiple peer support groups: More than 1 peer support affiliation provided

“Finger Lakes”: Most likely refers to Finger Lakes Regional Burn Association

List of abbreviations:

| | |
|--------------|---------------------------------------------------|
| LIBRE | Life Impact Burn Recovery Evaluation |
| PTSD | posttraumatic stress disorder |
| SOAR | Phoenix Survivors Offering Assistance in Recovery |
| TBSA | total body surface area |

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Table 1

Study population characteristics by burn survivor peer support participation

| Variable | Value | All Participants | Participated in Burn Survivor Peer Support | Did Not Participate in Peer Support | P |
|---------------------------|------------------------------------------------|------------------|--------------------------------------------|-------------------------------------|-----|
| All participants | | 596 (100) | 330 (55.4) | 266 (44.6) | |
| Age at time of survey (y) | 30 | 157 (26.3) | 85 (25.8) | 72 (27.1) | .47 |
| | 31–50 | 206 (34.6) | 107 (32.4) | 99 (37.2) | |
| | 51–65 | 177 (29.7) | 106 (32.1) | 71 (26.7) | |
| | >65 | 55 (9.2) | 31 (9.4) | 24 (9) | |
| | Missing | 1 (0.2) | 1 (0.3) | 0 (0) | |
| Sex | Female | 326 (54.7) | 172 (52.1) | 154 (57.9) | .14 |
| | Male | 269 (45.1) | 158 (47.9) | 111 (41.7) | |
| | Missing | 1 (0.2) | 0 (0) | 1 (0.4) | |
| Race/ethnicity | White non-Hispanic | 463 (77.7) | 252 (76.4) | 211 (79.3) | .63 |
| | Black or African American | 56 (9.4) | 32 (9.7) | 24 (9) | |
| | Hispanic/Latino | 40 (6.7) | 26 (7.9) | 14 (5.3) | |
| | Other* | 33 (5.5) | 18 (5.5) | 15 (5.6) | |
| | Missing | 4 (0.7) | 2 (0.6) | 2 (0.8) | |
| Education level | High school or less | 246 (41.3) | 131 (39.7) | 115 (43.2) | .46 |
| | Technical/trade training or associate's degree | 99 (16.6) | 62 (18.8) | 37 (13.9) | |
| | Bachelor's degree | 165 (27.7) | 90 (27.3) | 75 (28.2) | |
| | Graduate/professional/advanced degree | 84 (14.1) | 46 (13.9) | 38 (14.3) | |
| | Missing | 2 (0.3) | 1 (0.3) | 1 (0.4) | |
| Marital status | Married/live with significant other | 268 (45) | 142 (43) | 126 (47.4) | .31 |
| | Single/divorced/widowed/separated | 327 (54.9) | 187 (56.7) | 140 (52.6) | |
| | Missing | 1 (0.2) | 1 (0.3) | 0 (0) | |
| Current work status | Working | 321 (53.9) | 177 (53.6) | 144 (54.1) | .99 |
| | Not working | 190 (31.9) | 105 (31.8) | 85 (32) | |
| | Other | 84 (14.1) | 47 (14.2) | 37 (13.9) | |
| | Missing | 1 (0.2) | 1 (0.3) | 0 (0) | |
| TBSA burned (%) | 0–20 | 143 (24) | 65 (19.7) | 78 (29.3) | .01 |
| | 21–40 | 180 (30.2) | 103 (31.2) | 77 (28.9) | |

| Variable | Value | All Participants | Participated in Burn Survivor Peer Support | Did Not Participate in Peer Support | P |
|--------------------------------------|---------|------------------|--------------------------------------------|-------------------------------------|------|
| | 41–60 | 116 (19.5) | 67 (20.3) | 49 (18.4) | |
| | 61–80 | 85 (14.3) | 55 (16.7) | 30 (11.3) | |
| | 81–100 | 33 (5.5) | 24 (7.3) | 9 (3.4) | |
| | Missing | 39 (6.5) | 16 (4.8) | 23 (8.6) | |
| Burns to critical areas [†] | Yes | 484 (81.2) | 273 (82.7) | 211 (79.3) | .29 |
| | No | 112 (18.8) | 57 (17.3) | 55 (20.7) | |
| Time since burn injury (y) | <3 | 154 (25.8) | 66 (20) | 88 (33.1) | <.01 |
| | 3–10 | 164 (27.5) | 99 (30) | 65 (24.4) | |
| | >10 | 278 (46.6) | 165 (50) | 113 (42.5) | |

NOTE: Values are n (%) or as otherwise indicated.

* Other race/ethnicity includes Asian (n=8), American Indian or Alaskan Native (4), Native Hawaiian or Pacific Islander (2), multiracial (16), or unreported other race/ethnicity (3).

[†] Burns to critical areas: face, hands, feet or genitals.

Table 2

Mean scale scores by burn survivor peer support participation

| Measure | Peer Support Attendance | Sexual Relationships | Family and Friends | Social Interactions | Social Activities | Work and Employment | Romantic Relationships |
|---------------|-------------------------|----------------------|--------------------|---------------------|-------------------|---------------------|------------------------|
| Mean \pm SD | Yes | 50.0 \pm 11.7 | 51.2 \pm 10.4 | 48.4 \pm 9.6 | 53.2 \pm 9.8 | 50.5 \pm 8.9 | 48.8 \pm 11.3 |
| Number | | 227 | 329 | 329 | 329 | 175 | 330 |
| Mean \pm SD | No | 49.1 \pm 10.9 | 50.6 \pm 10.7 | 46.2 \pm 10.2 | 51.4 \pm 11.0 | 48.4 \pm 9.9 | 47.4 \pm 12.4 |
| Number | | 188 | 265 | 265 | 265 | 143 | 264 |
| <i>P</i> | | .45 | .55 | .01 | .04 | .05 | .13 |

Table 3

Linear regressions, participation in peer support and scale scores

| Scale | Crude Results | | | Adjusted Results* | | |
|------------------------|---------------|---------------|------|-------------------|---------------|-----|
| | β | 95% CI | P | β | 95% CI | P |
| Sexual Relationships | 0.90 | -1.34 to 3.14 | .43 | 0.26 | -1.95 to 2.48 | .82 |
| Family and Friends | 0.59 | -1.14 to 2.32 | .50 | 0.15 | -1.60 to 1.90 | .87 |
| Social Interactions | 2.22 | 0.58 to 3.87 | <.01 | 1.70 | 0.10 to 3.30 | .04 |
| Social Activities | 1.56 | -0.16 to 3.29 | .07 | 1.34 | -0.33 to 3.02 | .12 |
| Work and Employment | 1.62 | -0.50 to 3.75 | .13 | 0.96 | -1.11 to 3.02 | .36 |
| Romantic Relationships | 1.44 | -0.52 to 3.39 | .15 | 0.85 | -1.11 to 2.82 | .39 |

Abbreviation: CI, confidence interval.

* Adjusted models include sex, TBSA, and time since burn injury.

Table 4

Percentage of participants reporting better outcomes (4 or 5 on Likert scale) on the Social Interactions scale stratified by participation in support on the Social Interactions scale, stratified by participation in peer support

| Item | Percent Reporting Better Outcomes: Received Peer Support | Percent Reporting Better Outcomes: Did Not Receive Peer Support | Difference |
|--------------------------------------------------------------------------|----------------------------------------------------------|-----------------------------------------------------------------|------------|
| Because of my burns, it is hard for me to make friends. | 78.2 | 66.0 | 12.2 |
| I dress to avoid stares. | 55.0 | 42.9 | 12.1 |
| I avoid doing things that might call attention to my burns. | 57.2 | 46.0 | 11.1 |
| I avoid going to community events. | 72.9 | 62.3 | 10.7 |
| I avoid being with others because of my burns. | 78.3 | 68.3 | 9.9 |
| I limit going out in public because of my burns. | 80.4 | 70.5 | 9.9 |
| I am upset when strangers avoid looking at me. | 59.6 | 49.8 | 9.8 |
| Because of my burns, I feel uncomfortable in social situations. | 64.3 | 55.3 | 9.0 |
| I am uncomfortable going out with friends. | 84.9 | 77.0 | 7.9 |
| Because of my burns, I am uncomfortable around strangers. | 59.0 | 51.1 | 7.9 |
| I find it difficult to invite a friend to do something together. | 78.6 | 70.8 | 7.8 |
| I limit my activities because of how my burns look. | 63.0 | 55.5 | 7.5 |
| I do not go to parties because of how my burns look. | 77.6 | 70.3 | 7.3 |
| I feel embarrassed about my burns. | 61.1 | 53.8 | 7.3 |
| Because of my burns, I avoid strangers. | 75.6 | 68.6 | 7.0 |
| I feel uncomfortable in crowds because of my burns. | 61.6 | 54.6 | 7.0 |
| Because of how my burns look, I am uncomfortable when I meet new people. | 61.6 | 54.7 | 7.0 |
| I don't play sports because of how my burns look. | 77.8 | 70.9 | 6.9 |
| I don't worry about other people's attitudes towards me. | 59.9 | 53.0 | 6.9 |
| I avoid making new friends because I don't want to talk about my burns. | 85.0 | 78.8 | 6.2 |
| I feel like I don't fit in with other people. | 57.0 | 51.7 | 5.3 |
| I am uncomfortable with friends because of my burns. | 88.6 | 84.2 | 4.4 |
| I am upset when strangers comment on my burns. | 56.3 | 51.9 | 4.3 |
| I can help strangers feel comfortable around me. | 84.0 | 80.1 | 3.9 |
| My friends are uncomfortable with me showing my burns in public. | 80.8 | 77.3 | 3.4 |