

Perspectives on research participation feedback: Results from burn survivor focus groups

A study by the Burn Model System

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Background and Objective:

Research participants often receive little to no feedback after participating in a research study. We sought to better understand what information burn survivors might want to receive about the responses they provided as a part of a research study, and what formats are most useful.

Methods

A total of 11 burn survivors and 4 caregivers/partners participated in three focus groups at Burn Model Systems centers. Multiple formats of reports on health domains (e.g. pain, depression, itch) were provided and discussed. Understandability of the information, preferred format (graph, table, list), and opinions about the formats and content were discussed.

Highlights

Burn survivors were overwhelmingly interested in receiving summary reports of their responses to research surveys regardless of if they were positive or negative. Most said they would share the results with their caregivers and only a few would share with care providers. Simple displays, with an option to see more detailed information and supportive messaging are essential for the reports to be useful. More research is needed to evaluate the roles the report may play in recovery and to develop strategies for reaching out to survivors in distress.

What Did Work

- A simple summary of “okay” and “not as well” areas was easiest for participants to understand and not too harsh
- For participants who want more information they can click on the topic to get both graphical and table results of actual scores

Health Summary and Resources

This is a summary of your health and symptoms based on your responses to the survey. We also included some helpful links to health information. *Thank you for participating!*

Click on the topic or symptom to get more detailed information about your actual scores.

Your Health and Symptoms

You are **doing okay** in these areas.

Physical Function

You are **not doing as well** in these areas.

Depression
Anxiety
Itch
Fatigue
Satisfaction with Life
Sleep

Click to get detailed results

Talk to a counselor or doctor if you are concerned about these results. You can also contact us BMS Center name at XXX-XXX-XXXX or email@center.com if you have questions about your scores.

Fatigue

Time Since Your Burn Injury	Your Fatigue Score	Other People With Burns in Our Study
6 months	55	49
12 months	56	48
2 years	58	49

Scores range from 0 (no fatigue) to 100 (severe fatigue). Typical scores are about 50. Changes of 5 points or more could be important.

Your fatigue score is high. If you are concerned about fatigue talk to your doctor.

The picture below shows your results in a different way. This is the same information as the table.

Blue dots on the graphs are your scores. When the line goes down on the graph it means you're feeling better. If only one dot or part of the line is showing that means we do not have information from you at all time points.

More Fatigue
Less Fatigue

- Clear and detailed information on how to interpret the scores, graphs, and tables was required for participants to understand the information provided

Alcohol and Drug Use

You may have some questions about your drug and alcohol use.

If you would like more information about alcohol or drug abuse, here are some helpful websites.

<http://drughelpline.org/>
<https://www.niaaa.nih.gov/alcohol-health/support-treatment>
<https://www.drugrehab.com/>
<https://www.healthline.com/health/alcohol-addiction-support-groups>

Stress related to trauma

Managing stress related to trauma may be difficult for you.

If you haven't already talked to your doctor, that might be a good resource. These links might also be helpful:

<https://mskcc.org/burn-topics/ptsd>
<https://mskcc.org/burn-topics/psychological-distress>
<https://www.nami.org/learn-More-Mental-Health-Conditions/Posttraumatic-Stress->

- Participants felt alcohol, drug, and stress resources could be provided to everyone regardless of how they scored
- Simple messaging with links was preferred for feedback on these topics

What Did Not Work

- Graphs were difficult for most participants to interpret
- Multiple symptoms on one graph was confusing
- Participants didn't know what was being graphed and how researchers arrived at scores



Satisfaction with Life

	Your Satisfaction with Life Score	Other People With Burns	General Population Normal Range
6 months	31	21	20-24
12 months	31	21	20-24
2 years	31	22	20-24

- Tables seemed easier to interpret;
- Participants did NOT want to be compared to the general population or a sample of people with similar burn surface area

Health Summary and Resources

This is a summary of your health and symptoms based on your responses to the survey. We also included some helpful links to health information. *Thank you for participating!*

Click on the topic or symptom to get more detailed information about your actual scores.

Health and Symptoms

You reported **doing well** and feeling good in these areas.

Depression
Anxiety
Fatigue
Pain
Satisfaction with Life

You reported **doing okay** in these areas.

Sleep
Physical Function
Social Stigma
Itch

You reported **having problems** in these areas. Consider talking about these with your doctor or a medical provider.

None

It's great to see you doing well in so many areas!!

Compared to your answers on April 19, 2018, today...

You report doing better with:

Anxiety
Sleep Problems

You report doing about the same with:

Physical Function
Social Stigma
Depression
Itch

You report doing worse with:

Fatigue
Satisfaction with Life

You may want to talk to a counselor or doctor about your worsening fatigue or satisfaction with life.

- Red box was received as too “harsh”
- Differences between top and bottom boxes were not understood
- This was too much information to process

In general...

- Participants did NOT think it wise to provide negative feedback before 1-year post-burn
- It was difficult to provide less good news; participants felt like they failed/didn't try hard enough

FUNDING

The contents of this poster were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90DP0053 and H133P120002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this poster does not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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