

Examination of Health Information Needs of Caregivers of and Individuals with Burn Injuries

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Burns are a leading cause of trauma worldwide with about 450,000 burn injuries being treated at medical facilities in the United States each year. Finding relevant information on the long-term consequences of burn injuries is a significant challenge for many individuals with burn injuries and their caregivers. This qualitative study aimed to identify how individuals with burn injuries and caregivers of individuals with burn injuries prefer to access and use health information, identify obstacles to accessing useful information, and identify information most needed by burn survivors and caregivers. Participants were recruited through hospital listservs, websites, social media, and word of mouth from across the United States. Semi-structured interviews were conducted with 23 individuals, 12 with burn injuries and 11 caregivers of individuals with burn injuries. Three specific needs were identified: (1) more direction from health professionals in finding health information relevant to burn injuries; (2) more internet-based access points that connect individuals to appropriate support networks; and (3) more support for long-term consequences of burn injuries, specifically with psychological, social, and other chronic physical issues. Participants identified various needs in finding relevant health information, thereby highlighting gaps in current literature and the dissemination of current literature. One potential way to address these deficiencies is to consider user-centered design principles in developing research, by more directly involving individuals with burn injuries and caregivers as part of the research team.

Burns are the fourth leading cause of trauma worldwide.^{1,2} Approximately 450,000 burn injuries are treated at medical facilities in the United States each year, with about 10% of those requiring hospital admission.³ Burns are complex traumatic injuries, and much of the research focus has been on acute treatment, with increasing survival and reducing scarring being the primary foci.⁴ But, burns can also lead to many chronic complications, including reduced quality of life and increased disability.⁵⁻⁷

The impact of burn injuries is not confined to the impact on the individual, as family who become caregivers, are also impacted.^{8,9} Anxiety, depression, and post-traumatic stress disorder-related symptoms were found in spouses and close relatives of burn survivors.¹⁰ These symptoms were assessed in

the acute phase and there have not been investigations of the long-term consequences of burn injury caregiving. However, extrapolating from other injuries, caregivers may carry a heavy burden on their health and well-being in long-term caregiving situations.^{11,12}

Caregivers are expected to provide care, both in the acute phase (eg, wound washing, skin moisturizing) and in long-term care (eg, scar care, psychological sequelae). Therefore, they need access to health information to assist in decision-making and ensure that proper care is being utilized for the burn injuries. The health information needs may be different for caregivers and burn survivors, but this has not previously been investigated.

With the increased access to health information via mass media and the internet, it is important to understand current information needs and how burn survivors and caregivers find health information resources.¹³ By identifying burn survivors' and caregivers' current information needs and health information resources, it will assist with presenting information in a manner that meets the end users' needs. Access to relevant and trusted health information is necessary for caregivers and individuals with burn injuries to be active participants in care and recovery, both from the physical, functional, and psychological effects of burns.^{14,15} In general, the literature on burn injury has focused on the acute phases of burn injury, but with increasing recognition of burn injury as a life-long condition,^{4,16} it is imperative that burn survivors and their caregivers have access to health information resources that serve their long-term needs.

Therefore, this study aimed to identify how individuals with burn injuries and caregivers of individuals with burn injuries prefer to access and use health information, identify obstacles to accessing useful information, and identify information most needed by burn survivors and caregivers.

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METHODS

Sample

Twenty-three participants were recruited through hospital listservs, websites, social media, and word of mouth from across the United States. Participants included 12 individuals with burn injuries and 11 caregivers of individuals with burn injuries. Individuals with burn injuries who participated in the study were 44.3 years old on average and mostly female (75%), Caucasian (75%), had some college or were college graduates (75%), were unmarried or divorced (58%), and were employed (67%). All burn survivors had health insurance and most reported being in good, very good, or excellent health (67%). On average, the burn injury had occurred about 16.25 years ago (Table 1).

Caregivers were 49.4 years old on average, mostly female (91%), Caucasian (73%), married (73%), employed (64%), had some college or college graduates (82%), and reported being in good, very good, or excellent health (91%). The caregivers who participated in the study were parents (55%), spouses (18%), children (18%), or siblings (9%) of burn patients. The participants indicated they had been caregivers for someone with a burn injury for between 2 and 19 years or 8.7 years on average (Table 2).

Data Collection and Analysis

Interviews were conducted using a semistructured interview guide. The first portion of the interviews focused on identifying how participants find information, the ease or difficulty of finding reliable/reputable information, and the use of information related to addressing the effects of burns. The second portion of the interview explored the interest in and history of participating as a member of research teams. Participants responded by Likert scale to indicate relative ease or difficulty of finding health information and to the importance of finding reliable information. Other questions were open ended or requested yes/no responses. Participants were asked to explain their responses to yes/no questions.

The interviews were recorded and transcribed. Three researchers independently coded participant responses to

interview questions using a deductive coding technique from the transcribed recording; this included categorizing response sentiments (eg, very easy or nearly impossible to find health-related information on condition, yes or no). The predefined set of codes was established using the structure of the discussion guide. Coding accuracy or consistency between the two researchers was verified after coding two interviews.

A fourth researcher participated to identify themes in the deductively coded responses; the fourth researcher was responsible for ensuring consistency in definitions of themes to avoid researcher bias. The four researchers collectively explored the relationships between categories of information and identified themes/patterns in participant responses. The information was re-coded according to the theme best represented by the response.

RESULTS

Ease or Difficulty of Finding Information

Study participants indicated that finding health-related information was both easy and difficult. Participants who rated some aspect of finding information easy had good access to healthcare providers, access to and a positive experience with searching the internet, and/or participated in a support group. Accessible healthcare providers included friends, acquaintances, or providers with whom participants built a rapport with over time. Several healthcare organizations with burn centers were identified as having strong programs to educate persons injured by burns or caregivers of those with burns. Study participants shared that multidisciplinary provider teams in these healthcare organizations were helpful in addressing different aspects of information needs, from physical to emotional, that were helpful in their recovery. Participants with education in health or science related fields noted that their knowledge made searching for and finding information on the internet and from other sources easier. Several participants noted that their ability to interact with others who had lived experiences with burn injuries, either through support groups or camps, made getting relevant and useful information about burn injury easier.

Table 1. Patient demographic characteristics

ID	Age	Gender	Race/Ethnicity	Years Since Injury	Marital Status	Employed?
Average	44 ± 16	75% Female	75%Caucasian	16 ± 11	42%Married	67%Yes
119	61	Female	Caucasian	10	Not married	Yes
125	51	Male	Caucasian	33	Married/Partner	No
128	23	Male	Caucasian	5	Married/Partner	Yes
129	26	Male	Caucasian	9	Married/Partner	Yes
130	64	Female	African-American	19	Not married	No
131	43	Female	Caucasian	23	Married/Partner	Yes
132	61	Female	Caucasian	8	Married/Partner	Yes
133	25	Female	Caucasian	8	Not married	Yes
134	37	Female	Caucasian	18	Not married	Yes
135	29	Female	Caucasian	8	Not married	Yes
136	65	Female	Caucasian	40	Divorced	No
137	46	Female	African-American	14	Not married	No

Average row presents mean ± standard deviation for continuous variables and percentage for categorical variables.

Table 2. Caregiver demographic characteristics

ID	Age	Gender	Race	Ethnicity	Marital Status	Relationship to Recipient	Recipient Age	Recipient Gender	Years Since Injury
Average	49 ± 11	91% Female	82% Caucasian	18% Hispanic	73% Married	55% Parent	28 ± 21	73% Female	11 ± 7
232	46	Male	African American	Not Hispanic	Single	Parent	18	Female	13
233	41	Female	Caucasian	Not Hispanic	Married	Child	14	Male	8
234	61	Female	Caucasian	Not Hispanic	Married	Child	32	Female	19
235	37	Female	Multiple races	Hispanic	Married	Parent	16	Female	12
236	35	Female	Caucasian	Not Hispanic	Married	Parent	9	Female	5
237	55	Female	Caucasian	Not Hispanic	Married	Parent	25	Female	23
238	46	Female	Caucasian	Not Hispanic	Married	Parent	18	Female	17
239	42	Female	Caucasian	Hispanic	Widowed	Parent	4	Female	12
240	66	Female	Caucasian	Not Hispanic	Married	Spouse	65	Male	4.5
241	66	Female	Caucasian	Not Hispanic	Married	Spouse	65	Male	3.5
242	48	Female	Caucasian	Not Hispanic	Divorced	Sibling	45	Female	2

Average row presents mean ± standard deviation for continuous variables and percentage for categorical variables.

I have good friends in the medical and allied medical community. So [I get information] from burn staff, nurses, OTs, PTs, as well as massage therapists that specialize in burns... Participant 136 (Burn Survivor)

Participants who indicated that finding information was difficult attributed it to the absence of available research about the long-term effects, progression of injury, and uniqueness of individual experiences with burns. Beyond initial treatment, individuals with burn injuries and caregivers expressed interest in understanding the likely chronic and long-term physical and non-physical effects of burn injuries.

The lack of research on burns as a chronic injury. They sew us up, they heal our wounds, we heal our wounds and then we're kind of left out in la la land to find those answers on our own. Participant 132 (Burn Survivor)

Process for Finding Information

Participants relied on healthcare providers for specific information about treatment options, expected progression of recovery, and to validate information learned from other sources of information. However, the most common process used to find information was search of the internet. Participants used key word searches to gather more information about subjects discussed with their healthcare providers, to find general information about burns, and to discover specific treatment options. Key words or search terms including, “burn injury,” “burn survivor,” and “laser surgery” were offered as examples. From initial key word search, participants used a branching technique to find additional information if the initial search did not satisfy their information needs. Participants also relied on information from others to identify search terms or specific internet sites for finding useful information. Participants noted that finding specific information on the internet requires in-depth searching and critical appraisal.

I had a question I would probably pull up a web browser, open up Google and just type in my question and click on the

various links that would pop up and read what I would see on the screen and then click something else, and I guess that would be my search process. Participant 233 (Caregiver)

Key words would be like how they describe people with burn injuries. So, using words like survivors or even just how they described the burn injury...I'll casually like just type in like burn survivors and mental health and things like that. Participant 135 (Burn Survivor)

Sources of Information

Participants discussed sources that provided the most useful information about burns and described what made those sources helpful. Common sources of information used included the internet, healthcare providers, and support groups. Some participants used research articles, although this was less common. Occasionally, books and magazines were mentioned as a source of information.

The internet was the most commonly used source for information. Participants noted that the internet was helpful for finding information to supplement topics discussed with healthcare providers, getting answers to new questions when healthcare providers were not available, and connecting with individuals who have similar injuries or experiences. Participants also discussed the shortcoming of using of the internet as a source of information. These included inconsistencies between different sources on the internet, difficulty finding specific information, difficulty determining the accuracy of information, fear of misinformation, difficulty finding information in layman's terms, and uncertainty around how to search for information.

Being able to ask those questions – clinical questions at night, difficult to reach actual people and trying to be cognizant and aware of their time, and that's when the internet was available and easy to use. Participant 233 (Caregiver)

Healthcare providers were thought to be a source of trusted, reliable, specific, and personalized information. Participants

felt healthcare providers were best able to provide information on the projected progression of recovery from their burn injury.

The hospital's more tailored to me because they know my whole history and based on what's worked and what's not worked for me. So, I feel like they're better to answer for me. They're definitely more official when it comes to answering than the Facebook group. Facebook group's more just like a casual discussion board. Participant 133 (Burn Survivor)

Participants also noted drawbacks and issues associated with using healthcare providers as a source of information. Issues included a lack of information given by providers upon discharge, a lack of specific training or knowledge about newer treatments with some providers, and difficulty finding and accessing specialized physicians.

There was no sit down and this is what is going to happen, this is how you need to handle it. I just kind of felt like we were just kind of pushed out of the hospital and here, come back every week for therapy and that was kind of – and then we would come back every month or so to have them evaluate how she was healing, but other than that, I don't feel like there was information there for us. Participant 238 (Caregiver)

Support groups were thought to be a useful source of information. Individuals discussed in-person support groups, online support groups (eg, groups on Facebook), and burn camps. Participants mainly highlighted the ability of support groups to give access to valuable experiential knowledge and promote collaboration as well as garner social support, and perhaps even give hope to survivors. Participants citing online support groups as a resource also mentioned the accessibility as a benefit.

Many people tell their stories, whether it's at camp or on Facebook. But a lot of people are looking to have some of their questions answered through others' experiences. Participant 131 (Burn Survivor)

Despite the unique benefits offered by support groups, participants also discussed some issues surrounding support groups. These consisted of difficulty finding a support group, difficulty in assessing the applicability or reliability of the information gained in support groups, and the feeling that information shared by other individuals is not generalizable.

Reliability of Information

Participants emphasized the importance of finding reliable information about burns and burn treatments and described how they attempt to ensure the information they use is reliable. Three strategies or criteria for finding reliable information were identified: reputation and credentials of the organization or individual, type of publication, and consistency with other sources of information.

I tend to look at a lot of them and see which ones give me the same information as opposed – Because there's so much information out there, and I've kind of learned that, you know, if one site says this and 10 others say something totally different, then that website probably doesn't have the correct (laughs) information. Participant 238 (Caregiver)

Seeking information from reputable organizations and individuals was the leading strategy identified. Specific organizations like burn centers, professional or non-profit organizations, or academic institutions known to publish research on burns and burn treatments were considered to provide the most reliable information. Participants also indicated reliance on healthcare providers for reliable information. Although some participants described taking steps to verify the credentials or backgrounds of the individuals (or groups of individuals), other participants described having inherent trust in the information and decisions from their healthcare providers due to their education and specialization.

The type of publication was one consideration for determining reliability of information. Publications from the type of organizations listed above were thought to be more reliable than information found in magazines, newspapers, social media, or blogs. Another commonly cited method of determining the reliability or credibility of information was to cross-reference with other sources of information. Participants considered whether new information in light of their previous personal experiences. Specifically, they described using “common sense” to evaluate

I tend to look for the .orgs, .edus, and anything that is from the ABA, burn centers that I know are in existence that do research. I don't go to WebMD, put it that way. Participant 132 (Burn Survivor)

whether new information was consistent with information gained from other experiences, their healthcare providers, or support groups.

Participants with experience relying on peer-reviewed journals or scientific studies described evaluating the study design and in particular considering whether the study sample was similar to or different than themselves (ie, determining if the findings were applicable to their situation). Other methods of assessing and ensuring reliability included assessing the validity of the study design of research articles and determining whether information posted on social media represented opinion or fact.

Burn Survivor and Caregiver Involvement in Research

The second part of the interviews involved discussions with participants about patient-involved research. Participants were asked to discuss their participation in research, interest in participating in future research, and recommendations related to future research. Most participants who joined this study were intrinsically motivated to share their experiences for the benefit of people in similar circumstances. Specifically, they were interested in contributing to the body of knowledge on issues around long-term outcomes and ability to improve the lives (eg, medically, socially, personally, and professionally) of others with burn injuries. Two individuals expressed that their initial motivation was the financial incentive, but later found appreciation in sharing information that would be useful to others. Most participants indicated interest in participating in future research on burn injuries. Those who indicated not being interested in participating cited time constraints.

The majority of participants believed that future research would benefit from including caregivers and individuals with burn injuries. Participants noted that burn survivors and caregivers can best define the needs of burn survivors and potentially drive the direction of research questions. Participants also discussed that experience of having a burn injury is unique, and how it would be beneficial to have that perspective when conducting research. In other words, participants believed that having a burn survivor's voice throughout a research project could be beneficial.

We would provide new insight because if you're part of a research team and you don't have burns, you might not know the exact questions to kind of ask. I mean or you might not think of something because you don't know oh, I didn't even think about how this pain would feel or anything. Participant 133 (Burn Survivor)

Oh, I think any time you can involve the people who have lived it, there's always that unique insight that those individuals have so they can see things from the inside out instead of looking from the outside in. Participant 233 (Caregiver)

Participants recommended future research on subjects that may increase quality of life. Participants also expressed a desire for research on new technology and new treatment, including new skin substitutes and grafts, treatment for tightness of scars, and pain management. Research on emotional topics, ranging from social support, mood, and mental health, was also mentioned by numerous participants. Other topics mentioned included research on caregiving, homecare for burns, and secondary conditions resulting from a burn injury. Participants also expressed interest in longitudinal research that extended understanding beyond the acute phases of injury and treatment.

I think really patients want to know how they can feel better, look better, and experience life more. How they can return to what was normal for them more quickly, whether that be work or function or interactions with other people, and some of those psychological aspects or functional aspects of just bringing back their level of normalcy. Participant 129 (Burn Survivor)

Participants recommended ways to improve the dissemination of and usefulness of burn-related health information for burn survivors, caregivers, and healthcare providers. Participants discussed a desire to have centralized resource to convey scientific findings in layman's terms and provide easier access to discuss burn-related issues with healthcare professionals. Other suggestions included ensuring that survivors are aware of certain resources and new research, removing paywalls to articles, communicating expert opinions to burn centers, increasing advocacy and awareness, and support for caregivers. Information that participants wished was better disseminated included where to find specialized physicians and how to care for wounds, and other issues, during and aftercare.

DISCUSSION

The heterogeneity of people with burn injuries and their caregivers makes developing and disseminating information

about burns and burn care a challenge. This study provides a qualitative analysis of discussions with caregivers of and individuals with burn injuries about their experiences searching for and using health-related information about burns. The purpose of this analysis is to provide perspectives that inform future research and the dissemination of research.

Participants in this study identified use of the internet as a primary source of information throughout their rehabilitation. They found the volume of information available to be both a challenge and a benefit. The challenge being that the information was not always useful or reliable. Much of the information available was not relatable to their circumstances or stages of rehabilitation, difficult to understand, and difficult to access. In terms of content, caregivers and individuals with burn injuries expressed the need for better and more information related to the chronic and long-term effects of burns, in particular to address social and psychologic effects. Participants indicated that peer reviewed publications, those which presumably are most reliable, are difficult to understand, do not address social and psychological issues relevant to the injured and caregivers, and are difficult to access unless associated with a university or other institution with paid access to journals. Participants expressed the need to have reliable and user friendly (ie, information in layman's terms) burn-related information disseminated in ways not currently available to them.

One potential way to address the deficit in current information available to caregivers and individuals with burn injuries is to consider user-centered design principles.¹⁷ That is to directly involve caregivers and individuals with burn injuries in research as part of research teams. User-centered design is a term used to describe the design process in which end-users influence how a design takes shape and later to test the usability for the intended audience. Assumptions made by clinicians and researchers when designing research may not provide the research and information needed to develop effective interventions in clinical or self-care or disseminate information in a way that is useful and/or accessible to the end user. Engaging burn survivors and caregivers at every stage of the design process may provide needed insights to design of burn-related research, web-based interventions and information resources that meet the needs of caregivers and individuals with burn injuries.¹⁸

Study Limitations

We acknowledge the findings from this study have some limitations. Perhaps most importantly, is the high level of educational attainment and socioeconomic status (SES) of the participants. The majority (78.2%) of the study participants had some college, an important marker of SES. This may have limited our findings relative to individuals with lower education and SES and burn injuries are more common and more severe in those groups.¹⁹

Conclusion

This study provides an in-depth analysis of the challenges faced by caregivers and survivors of burn injuries when searching for and using health information. Participants identified the transition from acute to chronic care as one of the areas that deserves more attention in addition to mental health and quality of life over the course of a lifetime. Participants encouraged

engagement of burn survivors and caregivers as members of research teams to enhance the usefulness and dissemination of burn-related research to the end-users of that information.

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