

# Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi

Brian S. Barnett<sup>a,b,c,d</sup>, Macjellings Mulenga<sup>d</sup>, Michelle M. Kiser<sup>e</sup>,  
Anthony G. Charles<sup>e,\*</sup>

<sup>a</sup> Department of Psychiatry, Massachusetts General Hospital, 55 Fruit Street, Boston, MA 02114, USA

<sup>b</sup> Department of Psychiatry, McLean Hospital, 115 Mill Street, Belmont, MA 02478, USA

<sup>c</sup> Vanderbilt University School of Medicine, Nashville, TN 37232-0740, USA

<sup>d</sup> Kamuzu Central Hospital, UNC Project, P-Bag 101, Lilongwe, Malawi

<sup>e</sup> Department of Surgery, University of North Carolina, CB#7228, Chapel Hill, NC 27514-7228, USA

## ARTICLE INFO

### Article history:

Accepted 23 September 2016

### Keywords:

Africa South of the Sahara

Burns

Malawi

Psychotherapy

Group

## ABSTRACT

**Objective:** While psychological care, including supportive group therapy, is a mainstay of burn treatment in the developed world, few reports of support groups for burn survivors and their caregivers in the developing world exist. This study records the findings of a support group in Malawi and provides a qualitative analysis of thematic content discussed by burn survivors and caregivers.

**Materials and methods:** We established a support group for burn survivors and caregivers from February–May 2012 in the burn unit at Kamuzu Central Hospital in Lilongwe, Malawi. Sessions were held weekly for twelve weeks and led by a Malawian counselor. The group leader compiled transcripts of each session and these transcripts were qualitatively analyzed for thematic information.

**Results:** Thematic analysis demonstrated a variety of psychological issues discussed by both survivors and caregivers. Caregivers discussed themes of guilt and self-blame for their children's injuries, worries about emotional distance now created between caregiver and survivor, fears that hospital admission meant likely patient death and concerns about their child's future and burn associated stigma. Burn survivors discussed frustration with long hospitalization courses, hope created through interactions with hospital staff, the association between mental and physical health, rumination about their injuries and how this would affect their future, decreased self-value, increased focus on their own mortality and family interpersonal difficulties.

**Conclusions:** The establishment of a support group in our burn unit provided a venue for burn survivors and their families to discuss subjective experiences, as well as the dissemination of various coping techniques. Burn survivors and their caregivers in Malawi would benefit from the establishment of similar groups in the future to help address the psychological sequelae of burns.

\* Corresponding author at: Gillings School of Global Public Health, University of North Carolina, 4008 Burnett Womack Building, CB 7228, USA. Fax: +1 919 9660369.

E-mail address: [anthchar@med.unc.edu](mailto:anthchar@med.unc.edu) (A.G. Charles).

<http://dx.doi.org/10.1016/j.burns.2016.09.027>

## 1. Introduction

Burns are a common cause of injury in sub-Saharan Africa, especially amongst children. An international study of pediatric burn survivors indicated that the highest incidence of these survivors is in Africa [1]. Poverty is a significant risk factor for burns, with 90% of burn deaths occurring in low and middle income countries [2]. Malawi has a high prevalence of burn, with one study demonstrating that they accounted for eleven percent of injuries occurring in pediatric patients from 0 to 16 years of age presenting to the emergency department [3] and four percent of all injuries for patients of any age [4]. In Malawi, burns are most likely to occur in individuals less than 5 years in age [5], in individuals with a seizure disorder [6], in the cold season and at evening time [4]. The majority of patients hospitalized for burns in Malawi are less than 30 years in age and most burns are due to scalding [4,5], though burns due to open flame predominate in patients with epilepsy [5-7].

The mortality rate from burn in Malawi is high, ranging from 11% in a hospital with a burn unit [8] to 27% in a hospital without one [4]. The strongest predictor of mortality for these patients is the total body surface area of the burn. Significant efforts in Malawi have helped increase the LA50 (percentage of body surface area burned that is lethal to 50% of patients). In the United States, most burn centers have achieved an LA50 of 90% or higher [9]. The LA50 is significantly lower in Malawi. However, following the establishment of a burn unit at Kamuzu Central Hospital in 2011 the LA50 for patients there rose from 14% to 39% [8].

Despite the surgical and resuscitative advances in Malawi that have led to decreased mortality and also allowed patients with larger burns to survive, there has been only minimal advancement in aiding patients in dealing with the psychological sequelae of burns, which include loss, grief and changes in one's body image. Psychological distress following a burn, even in individuals without a prior psychiatric diagnosis, is associated with longer hospitalizations and delayed recovery [10]. The fact that burns are most common in children less than five years of age in Malawi is also important, since children are most vulnerable to developing disorders of attachment at this age, especially during infancy. Preoccupation with body integrity is a hallmark of children from two and half to six years of age [11], which also makes burns in this age group particularly traumatic.

While psychological care, including supportive group therapy, is a mainstay of burn treatment in the developed world [11], a review of the literature revealed few reports of psychological support groups for burn survivors and their families in the developing world [12,13]. Though it likely affects survivor recovery, the impact of burns on family members of survivors is a neglected area of research [14]. Therefore, the intention of this article is to provide an account of what appears to be the first recorded support group for burn survivors and caregivers in Sub-Saharan Africa, outside of South Africa. We also sought to conduct a qualitative analysis to determine themes that were most often discussed by group participants.

## 2. Methods

### 2.1. Establishment of the psychological support group

Our support group was established as a cooperative endeavor by trauma surgeons (AG and MK), a psychiatry resident (BB) and a Malawian counselor (MM) in February 2012 in the burn unit at Kamuzu Central Hospital (KCH) in Lilongwe, Malawi. KCH is a tertiary care hospital with 600 beds, serving approximately five million people from Lilongwe and central Malawi. The burn unit at KCH was created in 2011 and averages between 25 and 40 patient admissions each month [15]. The unit has 31 beds and treats both adult and pediatric patients, while employing 10 nurses and two surgical clinical officers. The University of North Carolina Institutional Review Board and the Malawi National Health Sciences Review Committee granted ethical approval for this study. Though a majority of patients being treated on the unit were under the age of five years, the group was open only to patients age twelve or older due to its thematic content. Children under twelve were invited to participate in a play therapy group, which is not reported here. Though patients younger than twelve were not included in the study group, caregivers of any patient on the unit, regardless of age, were also invited to participate. Sessions were held at a set time for an hour on Thursdays for a total of twelve weeks from February-May 2012. Patients and their caregivers were personally invited to attend the group by the group leader or nursing staff. Written informed research consent was obtained from all group members. If a participant was under the age of 18, child assent was obtained along with parental/guardian consent.

### 2.2. Group process and format

Rather than solely offering medical information, the purpose of the group was to allow patients and their caregivers to discuss their emotions and struggles while finding mutual support from other group members. Sessions were conducted in Chichewa, the primary language of the area, and led by MM, a Malawian counselor who had completed undergraduate training in counseling.

The counselor usually initiated each session with the introduction of a topic for discussion. These topics included: the experience of being in a hospital, the relationship between psychological stress and patients' physical recovery, coping with physical and emotional pain following burns, managing epilepsy and other risk factors for prevention of burns following hospital discharge, stress management, depression following burns and benefits from participating in group therapy sessions. After introducing the topic, the counselor would speak for 5-10 min about it in a general manner to help facilitate group discussion. Formal scripts for each session topic were not prepared. Following examination of these particular topics by the counselor, the group was opened up for general discussion in an unstructured manner.

### 2.3. Data analysis

Descriptive data concerning participants was collected and stored in a Microsoft Excel spreadsheet. Data were analyzed

using Stata 12.0 (Stata Corporation, College Station, Texas, USA). Fisher's exact tests and Student's t-tests were used to assess for differences between study participants and eligible patients on the unit who declined or were not asked to participate. However, this investigation was primarily designed to be an exploratory qualitative study of a supportive group therapy intervention. Transcripts were compiled by MM based on notes taken during and after each support group session. These transcripts form the basis of our data analysis. Transcripts included issues brought up by group participants, as well as direct quotes. They were reviewed by two individuals (MM and BB) and analyzed using thematic analysis [16]. Transcripts were then coded using the open coding technique to search for recurring themes in subject matter. The themes coded by each reviewer were then compared and those themes on which both reviewers agreed are included in this analysis.

### 3. Results

#### 3.1. Participant characteristics

Thirty six patients who were 12 years of age or older were treated in the burn unit during the study period and eligible to participate (Fig. 1). Eighteen of these patients (6 female and 12 male) participated in group sessions. Twelve patients declined to participate in the sessions, with eight (67%) stating that they felt too unwell to participate, two (17%) stating that they did not

think the group would be helpful and two (17%) others declining for unknown reasons. Patients participating in the group were  $24 \pm 9$  years (range 12-45 years) in age. There were no statistically significant differences in characteristics between patient participants and eligible patients who declined to participate or who were not asked to participate (Table 1).

Forty-eight caregivers (35 female and 13 male) participated in the study and had a mean age of  $34 \pm 12$  years (range 19-63 years). An additional twenty-one caregivers were approached to participate, but declined to do so, with 10 (47%) stating that they would rather spend their time with the family member who was a patient and was not participating in the group, five (24%) stating they did not think the group would be helpful and six (29%) declining for unknown reasons.

The mean number of participants during each group therapy session was 13 (range: 5-23), which included  $4 \pm 2$  patients and  $9 \pm 5$  caregivers. The mean number of sessions attended was 3 (range 1-6) for patients and 4 (range 1-8) for caregivers. Cessation of attendance was most frequently due to the patient being discharged (10 patients, 56%) or the patient dying (3 patients, 17%). Two patients (11%) discontinued attendance due to not feeling well enough to continue, and three patients (17%) discontinued for unknown reasons.

Thirty one caregivers (65%) discontinued participation after the patient they were caring for was discharged or died. Our data recording process did not differentiate between whether the caregiver reason for discontinuation was patient discharge or death. Twelve caregivers (25%) discontinued attendance

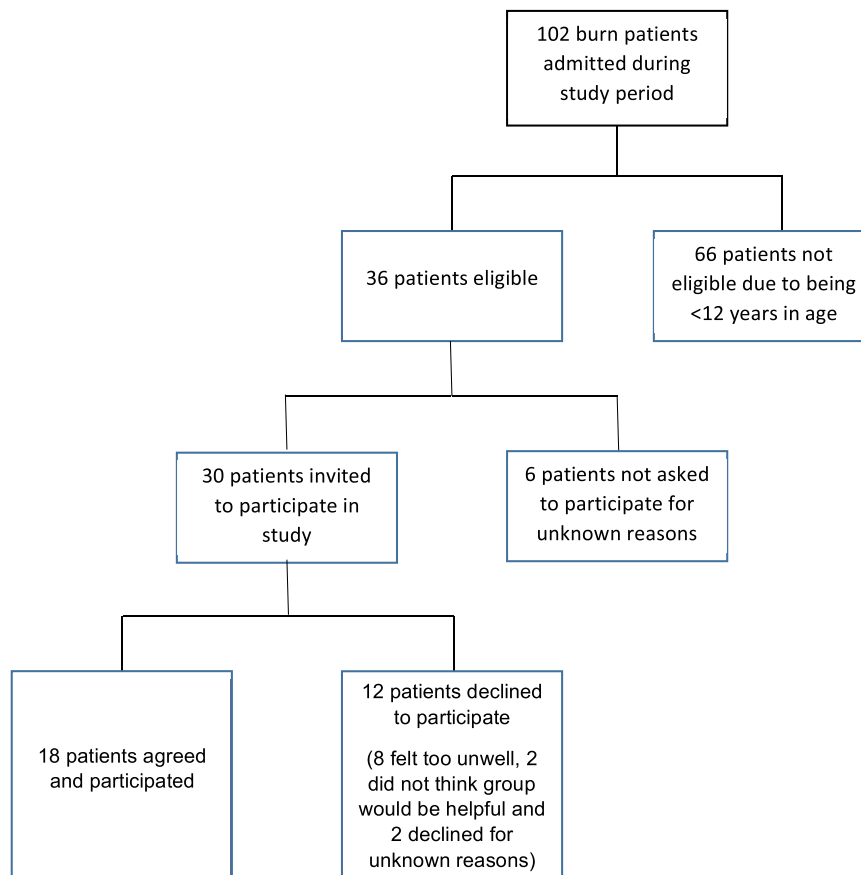


Fig. 1 – Study enrollment flowchart.

**Table 1 – Demographic and clinical characteristics of participants and non-participants.**

	All eligible patients on unit (36)	Group participants (18)	Group non-participants (18)	Statistical significance <sup>b</sup>
Age in years (Mean±SD)	29±16	24±9	34±19	0.07
Female (%)	11 (31)	6 (33)	5 (28)	1.00
Male (%)	25 (69)	12 (67)	13 (72)	1.00
Type of burn—flame (%) <sup>a</sup>	22 (61)	13 (72)	9 (50)	0.31
Type of burn—scald (%) <sup>a</sup>	13 (36)	5 (28)	8 (44)	0.31
% Total Body Surface Area Burned (Mean±SD)	21±24	19±17	22±30	0.75
Underwent surgical procedure (%)	18 (50)	11 (61)	7 (39)	0.32
Disposition—discharged (%) <sup>a</sup>	28 (78)	15 (83)	13 (72)	0.69
Disposition—died (%) <sup>a</sup>	7 (19)	3 (17)	4 (22)	0.69

<sup>a</sup> Percentages for these variables do not total to 100% due to missing data.

<sup>b</sup> Fisher's exact test for categorical variables and Student's t-test for continuous variables.

due to having to return to work or other duties outside the hospital, and five caregivers (10%) discontinued for unknown reasons.

### 3.2. Thematic analysis of session content

Analysis of the group leader's transcripts revealed several themes that were recurrently discussed by participants. These are discussed below, along with direct participant quotes that demonstrate the thematic material. For caregivers, the most common subject themes were:

- guilt and self-blame related to their children's injuries,
- how this guilt created an emotional distance between them and the patient,
- fear that being admitted to the hospital meant that their children would likely die,
- concerns about the future of their child and the stigma associated with burn scars.

The following quotes exemplify some of these themes:

- One mother of a pediatric patient stated, "It is my fault my child is here. I feel as though I was not caring for him properly. What will his future be like with all these scars? Will he have emotional problems? These questions keep repeating in my mind."
- One father of a pediatric patient admitted, "I am angry at myself, but I know this is not good for my daughter. I know this sends a message of no hope to her. That will only make her pain worse."
- Another mother reported, "When my child was burned and the clinical officer [at the clinic] directed us to KCH, I was fearful that he would die. Only people who are very ill go there. Since being here though, the nurses have given us hope and we have seen the medications do good things."

Patients discussed the following subject themes:

- frustration with long hospitalization courses,
- the hope that interactions with nurses and other staff members instilled,

- the link between their emotional state and physical recovery,
- struggles with rumination about their injuries and the impact on their future,
- decrease in self-value,
- being more cognizant of their mortality following the burns,
- interpersonal difficulties with family members.

The following are quotes from some patients in the group:

- One man admitted, "The fear of death was overwhelming. I could not move past it."
- An adolescent patient stated, "It is difficult to manage this stress by myself. Now my mother has left for home to attend to my brother, who is psychotic. This situation has removed a large part of meaning from my life. I cannot do this alone."
- One female patient observed, "I have realized that thinking about this too much makes my pain grow and my overall condition worse."

Group members provided one another with a variety of coping mechanisms, which included:

- maintaining a close emotional relationship with their children during this time [for caregivers],
- returning to the support group sessions,
- talking openly about their feelings with friends and family,
- relaxation techniques such as breathing exercises, thinking about positive aspects of their lives and praying/spiritual practices.

Related quotes include:

- One patient offered, "The best way I have found to deal with this stress is to keep speaking with your friends and guardians. You should also develop a network of relationships within the burn ward."
- One patient stated to another, "You should accept the fact that things can change and focus on your situation now."

Allow God to take control of your life.” Another added, “Put your suffering in the hands of almighty God.”

When questioned about their experiences in the group, members felt it was beneficial to see that others were suffering in situations similar to their own and to learn about how to maintain psychological wellbeing and manage stress. They also reported increased comfort in talking about burns, as well as reduced fears of the hospital environment and greater valuing of the importance of social support when dealing with challenging health situations.

- One mother of a patient stated, “This is the first time since coming to this ward that I have seen patients and guardians from different families come together to share experiences and learn from one another. I think this has value. I am worried though that we have not been told of any counseling for after discharge.”

#### 4. Discussion

This study demonstrates the first look at a psychological support group for caregivers of patients with burns in Sub-Saharan Africa, outside of South Africa [13]. Our support group was unique in that it also included patients. The psychological effects of burns on pediatric patients are well established. Two factors are related to psychological and social adjustment, which are the quality of family and social support that a patient receives and the willingness of the patient to take social risks. Poor prognostic factors include social shyness, learned dependence on family members, impaired family cohesion and high family conflict [17]. All of these factors are ones that can be addressed in the setting of a support group such as ours.

Given the complex needs of burn patients, hospital staff members are often unable to talk with family members other than to provide clinical updates and information about the treatment plan [18], which led to the establishment of the first recorded support groups for family members of burn patients. It is important to address the needs of family members of burn patients (especially parents in the case of child patients), to decrease psychological morbidity. It is known that the prevalence of depression in mothers of burned children exceeds that of the general population [19]. In a South African family support group, it was reported that blame and guilt of mothers is the most prominent theme because they are usually blamed for the child’s burn [13]. This is important not only for the health of the mother, but also the psychological recovery of the patient. Emotional distress in mothers of burn patients is associated with impaired psychosocial adjustment in adolescence for burned children [20]. Themes discussed in our support group by caregivers were similar to those reported elsewhere and included guilt and self-blame of parents [13], as well concerns about the future of their child and the stigma associated with burn scars [18]. Group members were also exposed to a variety of coping mechanisms that may be useful for them, such as maintaining close relationships between caregivers and patients, performing breathing exercises, being

more emotionally open with others and conducting spiritual practices.

Given our hospital’s limited resources, our support group also allowed for the inclusion of patients (some of whom were adolescents) in addition to caregivers. Psychological distress following a burn is associated with delayed physical recovery in patients and longer hospitalizations as well, primarily due to poor adherence and discharge issues [10]. Patients in our group discussed concerns about how their self-value had decreased due to their injury, how their future would be affected and how the experience of being burned had led them to think much more about their mortality. By addressing psychological distress in the setting of a support group, as we have done, patients may be able to decrease the amount of time they spend in the hospital following a burn through increased treatment adherence.

Previous research has shown that adolescent participants in burn support groups cited defining how one copes with being burned, meeting others who had similar experiences, expressing feelings about having been burned and learning new coping skills [21] as the most common benefits of participating in a support group. Themes of psychological growth reported by support group members include acceptance of self, perspective change, value of community, and reciprocity [22]. The facilitation of community and development of relationships with other group members have also been reported as particularly useful benefits of participation. Patients in our group noted the benefit of returning to the group each week and the value of having a community in the hospital to share their thoughts openly. The small sample size and short time frame is a limitation of our study. Due to having a limited number of study staff, there were also difficulties in inviting all eligible participants to participate and with obtaining complete data about participants and non-participants. Our study would also have benefited from audio recordings of each session to make our thematic analysis more accurate. Unfortunately, due to financial considerations the group was not able to continue past the study period. However, given the findings of this study, it is evident that a need for groups like this exists for patients receiving burn care in Malawi and their family members. In the future, it would be beneficial to conduct a study comparing patients and caregivers randomized to participate in a support group to those who were not, to see whether depressive and anxiety symptoms are improved following group participation, as well as length of patient hospitalization.

#### 5. Conclusions

Burns pose a serious threat to an individual’s physical, as well as psychological wellbeing. As burn care becomes more comprehensive in the developing world, more attention is now being paid to the psychological treatment of burn survivors. It is also important to address the psychological health of caregivers in this setting, since most burn victims are children and their recovery is heavily influenced by the wellbeing of those caring for them. The establishment of a support group in our burn unit provided a venue for burn survivors and their caregivers to discuss subjective

experiences, as well as the dissemination of various coping techniques. Future investigation should focus on assessing quantitative changes in mood and anxiety symptoms in group participants as measured by appropriate symptom scales and whether group participation is associated with decreased length of hospitalization.

### Conflict of interest

The authors declare that there are no conflicts of interest.

### Acknowledgements

This study was funded by the National Institutes of Health (NIH) Fogarty International Center Clinical Research Scholars and Fellows Program at Vanderbilt University (R24 TW007988).

BB received an NIH Fogarty-Fulbright fellowship from 2011 to 2012.

We are grateful to Christina Borba, PhD, MPH for technical assistance in preparing this manuscript.

### REFERENCES

- [1] Burd A, Yuen C. A global study of hospitalized paediatric burn patients. *Burns* 2005;31(June (4)):432-8.
- [2] Peck MD. Epidemiology of burns throughout the world. Part I: distribution and risk factors. *Burns* 2011;37(November (7)):1087-100.
- [3] Kiser MM, Samuel JC, Mclean SE, Muyco AP, Cairns BA, Charles AG. Epidemiology of pediatric injury in Malawi: burden of disease and implications for prevention. *Int J Surg* 2012;10: 611-7.
- [4] Samuel JC, Campbell EL, Mjuweni S, Muyco AP, Cairns BA, Charles AG. The epidemiology, management, outcomes and areas for improvement of burn care in central Malawi: an observational study. *J Int Med Res* 2011;39(3):873-9.
- [5] Komolafe OO, James J, Makoka M, Kalongeolera L. Epidemiology and mortality of burns at the Queen Elizabeth Central Hospital Blantyre, Malawi. *Cent Afr J Med* 2003;49(11-12):130-4.
- [6] Boschini LP, Tyson AF, Samuel JC, Kendig CE, Mjuweni S, Varela C, et al. The role of seizure disorders in burn injury and outcome in sub-Saharan Africa. *J Burn Care Res* 2014;35(6): 406-12.
- [7] Virich G, Lavy CB. Burns in Malawi. *Ann Burns Fire Disasters* 2006;19(4):171-3.
- [8] Tyson AF, Boschini LP, Kiser MM, Samuel JC, Mjuweni SN, Cairns BA, et al. Survival after burn in a sub-Saharan burn unit: challenges and opportunities. *Burns* 2013;39:1619-25.
- [9] Kasten KR, Makley AT, Kagan RJ. Update on the critical care management of severe burns. *J Intensive Care Med* 2011;26 (4):223-36.
- [10] Wisely JA, Wilson E, Duncan RT, Tarrier N. Pre-existing psychiatric disorders, psychological reactions to stress and the recovery of burn survivors. *Burns* 2010;36(March (2)): 183-91.
- [11] Brennan MM, Ceranoglu AT, Fricchione GL, Stoddard FJ. Burn patients. In: Stern TA, editor. et al. *Massachusetts General Hospital handbook of general hospital psychiatry*. 6th ed. Philadelphia, PA: Saunders; 2010. p. 383-96.
- [12] Dang R, Wang Y, Li N, He T, Shi M, Liang Y, et al. Effects of group psychological counseling on self-confidence and social adaptation of burn patients. *Zhonghua Shao Shang Za Zhi* 2014;30(December (6)):487-90.
- [13] Frenkel L. A support group for parents of burned children: a South African children's hospital burns unit. *Burns* 2008;34:565-9.
- [14] Stoddard FJ, Ryan CM, Schneider JC. Physical and psychiatric recovery from burns. *Psychiatr Clin North Am* 2015;38(March (1)):105-20.
- [15] Kiser M, Beijer G, Mjuweni S, Muyco A, Cairns B, Charles A. Photographic assessment of burn wounds: a simple strategy in a resource-poor setting. *Burns* 2013;39(1):155-61.
- [16] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77-101.
- [17] Blakeney PE, Rosenberg L, Rosenberg M, Faber AW. Psychosocial care of persons with severe burns. *Burns* 2008;34 (June (4)):433-40.
- [18] McHugh ML, Dimitroff K, Davis ND. Family support group in a burn unit. *Am J Nurs* 1979;79(December (12)):2148-50.
- [19] El Hamaoui Y, Yaalaoui S, Chihabeddine K, Boukind E, Moussaoui D. Depression in mothers of burned children. *Arch Women's Ment Health* 2006;9(May (3)):117-9.
- [20] Sawyer MG, Minde K, Zuker R. The burned child—scarred for life? A study of the psychosocial impact of a burn injury at different developmental stages. *Burns Incl Therm Inj* 1983;9 (January (3)):205-13.
- [21] Chedekel DS, Toliias CL. Adolescents' perceptions of participation in a burn patient support group. *J Burn Care Rehabil* 2001;22(July-August (4)):301-6.
- [22] Davis T, Gorgens K, Shriberg J, Godleski M, Meyer L. Making meaning in a burn peer support group: qualitative analysis of attendee interviews. *J Burn Care Res* 2014;35(September-October (5)):416-25.