



### Introduction

Interventions for burn-injured children (BIC) largely focus on the child with the physical injury while consideration for family systems appears incidental. This study aimed to gain insight into the perspectives and needs of parents/caregivers of pediatric burn patients (PPBP). When considering BIC within the context of a family system, it is reasonable to expect the injury to engulf everyone. The literature emphasizes the acute and lasting physical and emotional impact of burns. Moreover, research suggests PPBP experience an emotional response to the incident that is often complicated by physical absence from their other children. Thus, this exploratory study fills a gap by engaging the unique perspective of the PPBP and posits direct implications for essential program enhancement/development.

### Literature Review

Sustaining life of those impacted by burn trauma

Assessing the needs of family/caregivers

Evaluation

Aftercare 8 reintegration for individual with burn trauma

Program development for family/caregivers at acute hospitalization and aftercare & reintegration

Research has primarily been limited to the experience of the burn injured person. However, these life altering injuries produce lasting physical and psychosocial consequences that warrant further discussion for both the person who experienced the burn injury, as well as their family.

22 semi-structured interviews with parents of BIC in India reported a 3 stage process of embracing survival: 1) suffering the trauma alongside their burninjured child; 2) supporting the survival of their child; and 3) protecting the child from stigma as a result of the scarring and disfigurement. Parents also perceived a lack of support from both healthcare professionals and family members.

A Swedish study of six parents/caregivers suggested difficulties and worries regarding physical problems, altered family relations, changes to everyday life, and the need for parental/family support.

Some research has suggested that parents/caregivers experience their own emotional response complicated by physical absence of unharmed child(ren).

Significant gap in regard to understanding the impact of a burn injury from the emic perspective of family members.

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- Demograph Daught • Injury 2002 v was 20
- Son— • Injury 2011 w 9 years
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- Daugh • Injury 2004 v was 9
- Daugh Injury 2011 v was 6
- Son— • Injury 2014 w 9 years

**Childhood Burn Injuries: The Parent Perspective** Dana R. Dillard, Ph.D., MSW, LCSW Stacey R. Kolomer, Ph.D., MSSW Programs should address the needs of all family members, not only the burn injured child. The family system impact is a critical primary consideration for research and interventions.

# Methodology

ology	<ul> <li>Hermeneutic phenomenology approach guided by van Manen</li> <li>Explore experience of parenting a burn-injured child</li> </ul>
ment ection	<ul> <li>Family Weekend Program</li> <li>Injury not result of abuse or neglect</li> <li>Must be primary parent/caregiver of BIC</li> </ul>
lection alysis	<ul> <li>30-65 minutes interviews</li> <li>6 of 7 families attending the program participated (n=11)</li> <li>Qualitative Analysis using ATLAS.ti</li> </ul>



Table 1. Social, demographic and burn information of the participants (all names are pseudonyms).

Married Couple Biological Parents Mother—Donna 42 yrs old Father—David 40 yrs old Caucasian No religious affiliation Married Couple Biological Parents Mother—Rachel 42 yrs old Father—Bob 35 yrs old Caucasian Southern Baptist Married Couple Biological Parents Mother—Francine 38 yrs old
Biological Parents Mother—Rachel 42 yrs old Father—Bob 35 yrs old Caucasian Southern Baptist Married Couple Biological Parents
Biological Parents
Father—Jack 48 yrs old Latino Catholic
Married Biological Mother Mother—Debra 30 yrs old Caucasian No religious affiliation
Non-married couple Biological Mother and Stepfa Mother—Barbara 32 yrs old Stepfather—Adam 29 yrs old African American Baptist
Married Couple Biological Parents Mother—Twanda 44 yrs old

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What was event that caused the burn injury?

Describe what the experience of the burn event was like for you.

What do you wish other people understood about burn injuries?

Do you or the care recipient discuss the incident and/or the injury?

What support was offered to you at the time of the incident? Was it helpful? What was not helpful?

# **Common Experiences**

### Positive

- Strength of informal support networks
- Empowerment through educating others
- Creating new allies
- Mutual support from other families

### Negative

- Parental Guilt
- Isolation
- Marital Strain
- Sibling tensions
- Unknown prognosis
- Family member
- insensitivity
- Managing cruelty
- Physical/mental issues

# Lack of Sensitivity

"We couldn't even leave her with family and take a weekend to ourselves because every time I did physical therapy, if they were around they're like, "Why can't you just give her a break?"

# Neverending Treatment

"I wish that they understood that it's never over. When you break a leg, you get it set and then it re-heals and you forget about it....It's ten years later and we're still—it's our life. We go to Cincinnati. That's our life."

Conclusions Programs should address the needs of all family members, not just BIC. In order to mitigate the impact of burn trauma, the family system impact remains a critical primary consideration for research and interventions. Applicability of Research to Practice: Findings can contribute to program planning with increased consideration of the family system. As a result of this study, siblings are now included in a summer camp program historically serving only BIC and family camp occurs twice a year.



## References

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