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Adult survivors' lived experience of burns and post-burn health: A qualitative analysis

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ABSTRACT

Introduction: The individual implications of major burns are likely to affect the full spectrum of patients' physical, emotional, psychological, social, environmental, spiritual and vocational health. Yet, not all of the post-burn health implications are inevitably negative. Utilizing a qualitative approach, this heuristic phenomenological study explores the experiences and perceptions early (ages 18–35) and midlife (ages 36–64) adults providing insight for *how* participants perceived their burns in relationship to their post-burn health.

Methods: Participants were interviewed using semi-structured interview questions framed around seven domains of health. Interview recordings were transcribed verbatim then coded line by line, identifying dominant categories related to health. Categories were analyzed identifying shared themes among the study sample.

Results: Participants were Caucasian, seven males and one female. Mean age at time of interviews was 54.38 and 42.38 at time of burns. Mean time since burns occurred was 9.38 years with a minimum of (20%) total body surface area (TBSA) burns. Qualitative content analysis rendered three emergent health-related categories and associated themes that represented shared meanings within the participant sample. The category of "Physical Health" reflected the theme physical limitations, pain and sensitivity to temperature. Within the category of "Intellectual Health" were themes of insight, goal setting and self-efficacy, optimism and humor and within "Emotional Health" were the themes empathy and gratitude.

Conclusions: By exploring subjective experiences and perceptions of health shared through dialog with experienced burned persons, there are opportunities to develop a more complete picture of how holistic health may be affected by major burns that in turn could support future long-term rehabilitative trajectories of early and midlife adult burn patients.

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1. Introduction

Over the past 25 years advancements in protocols designed to treat health consequences associated with burns have ameliorated short-term patient outcomes and appreciably increased chances of survival from even the most massive burns [1–3]. Implications that impact long-term health outcomes such as functional and psychological adjustment [4], post-traumatic stress [5], social impact of disfigurement [6], vocational re-entry [7,8], and post-traumatic growth [9,10] have been explored both quantitatively and qualitatively, advancing knowledge of long-term bio-psycho-social needs of burn patients. It is important to remember that while each of these investigations are individually significant and provide tremendous value in the care of burned persons, health domains are inter-related and when viewed in unison, represent a more complete picture of long-term burn patient health.

Using seven domains to represent holistic health [11,12] as a framework for single, semi-structured face-to-face interviews, this heuristic phenomenological [13] study explored the phenomena of post-burn experiences and perceptions of early and midlife burned adults living in the Midwestern United States, providing insight into *how* study participants experience their post-burn health.

1.1. *Post-burn health*

During the 1970s, public health planners attempting to measure population health recognized that scales quantifying disease alone were insufficient [14]. Toward the end of the 20th century, quality of life surveys were developed to address functional, subjective health and relative well-being across populations exposed to various acute and chronic health conditions. Questions about how burns impact individual health and quality of life were operationalized in the latter years of the 1970s [15], followed by the first published quality of life survey focused on burn patients' behavioral, social and clinical outcome parameters [16]. The Burn Specific Health Scale (BSHS) continues to provide important objective data about health and quality of life following burns [17]. Yet, knowledge of patient health is deepened through qualitative studies assessing burn survivors' personal stories [18], providing additional understanding of how survivors' holistic health is challenged by burns. By exploring subjective experiences and perceptions of health shared through dialog with experienced burned persons, there are opportunities to develop a more complete picture of how holistic health and role reintegration may be affected by major burns that in turn could support future long-term rehabilitative trajectories.

Health is not a single unit but rather a grouping of inter-related domains that make up individual health [11,12]. Patient outcomes are sustained through physical, social, emotional, environmental, intellectual, spiritual [11] and vocational [12] aspects of health. Support for optimal long-term outcomes from burns through application of a holistic approach to health is advantageous in that each health domain will potentially influence patient behaviors and treatment compliance. Utilizing patient-centered goals, health-based follow-up is most effective through participation and collaboration among providers, patients and patients' support systems which include community resources. Perceptions developed by burn patients in their transition from hospital to home will likely influence subjective meanings attached to their individual burn experiences and long-term health. While it is understood that many of these perceptions are individual in nature, many commonalities are present, contributing to the body of knowledge that supports overall quality of burn care and patient recovery.

Erikson [19] believed there were eight serial psycho-social crises that individuals must overcome in order to successfully advance to the next stage of psycho-social development. Erikson's [19] early adulthoods crisis of intimacy vs. isolation (ages 18–35) pertains to development and maintenance of intimate relationships and generativity vs. stagnation in middle adulthood (ages 36–64) is focused on career satisfaction and contributing to future generations. Because Erikson [19] believed that each phase of life introduced different developmental issues, the effects of burn trauma are likely to impact patients in predictable ways based on the their current post-burn developmental phases.

This exploratory qualitative, heuristic study [13] aimed to explore the phenomenon of major burn on early and midlife adult survivors' holistic health. Heuristic methodology was chosen based on the primary investigator's long-term history as a burn survivor which was endorsed rather than dismissed, providing a unique point of view to the study. Investigators believed study participants would be more comfortable and expressive within interviews knowing that the interviewer/primary investigator had personally experienced many of the post-burn issues that are common in burn recovery. The format of the primary investigation was based on the outcome of a pilot study in which four long-term adult burn survivors treated in a different regional burn center were interviewed about their burn events and health. Inclusion and exclusion criteria for the participant sample as well as interview framework for this study were based on results from the pilot study.

2. Methods

Purposive sampling was utilized to gather rich, descriptive data from burned adults who had experienced major burns. Inclusion criteria for this primary study involved English-speaking females and males with an age range of 18–64 years with a minimum of (20%) total body surface area (TBSA) injuries that included deep partial- and full-thickness burns to the face, hands, feet, and/or joints. The TBSA inclusion criteria was aligned with the American Burn Association's (ABA) definition for major burns benefiting from specialized burn treatment and a threshold for decreased ''general health.'' [20, p. 22] Participants must have been discharged from their initial burn hospitalization at least 12 months prior to study interviews. There were no specific inclusion or exclusion criteria for family members who were selected by participants as being instrumental in their burn recoveries.

Exclusion criteria included persons who were younger than 18 years of age or 65 years or older at the time of their burns and those with burns that were less than (20%) TBSA. No