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Title

Social Participation of Burn Survivors: A Conceptual Framework

Introduction: The ability to objectively measure community reintegration following burn injury is critical to the design of therapies that optimize the recovery of burn survivors. This complex concept has no adequate metric for burn survivors. This project aims to develop and validate a conceptual framework for understanding the social impact of burn injuries in adults and develop an item bank for future use in a Computerized Adaptive Test to measure community reintegration in burn survivors.

Methods: We performed a comprehensive literature review and consulted with clinical experts and burn survivors about social life areas impacted by burns and modified items from established generic, burn-specific, and other condition-specific measures. We added original items to enrich the item pool. Three investigators independently classified items by subdomain; the research team reviewed items to ensure appropriate classification, and reached consensus on inclusion, modification, removal and addition of new items. Focus groups with burn survivors and clinicians were conducted to validate the framework and revise and augment the item pool. Transcripts were coded using grounded theory. The research team revised and crafted new items based upon focus groups analysis. Cognitive interviews with burn survivors were conducted to assess clarity and consistent interpretation.

Results: The World Health Organization's International Classification of Functioning, Disability and Health (ICF), was chosen to conceptually ground the emergent content model. The primary construct identified was social participation (referred to as social impact), which contains two major concepts--societal role and personal relationships--each with several subdomains. The seven subdomains chosen for item development were work/employment, recreation and leisure, relating to strangers, romantic, sexual, family and informal relationships. An initial pool contained 252 items that were tested for clarity and interpretation by burn survivors and reduced to a final pool of 192 items.

Conclusions: Qualitative results strongly suggest that the conceptual model fits the constructs for societal role and personal relationships with the respective subdomains. A large scale calibration study is currently underway which will lead to using IRT methods to develop a CAT for monitoring the social impacts of burn injuries during recovery.

Applicability of Research to Practice: This CAT measure will be the first to specifically identify the social aspects of burn survivor's life throughout the recovery process. The measure has the potential for integration into electronic health records, allowing for burn survivors and their care providers to measure the current social consequences of burn injuries, and track their trajectories throughout the recovery process.

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