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Heterotopic Ossification in adults following a burn: A phenomenological analysis



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ABSTRACT

Heterotopic Ossification (HO) is a rare but severely debilitating complication after a burn. Despite there being literature of varying quality explaining the postulated pathological process, risk factors and treatment for HO, the individual experiences of adults diagnosed with HO following a burn, remains unreported. This study sought to explore and describe burn survivors' experiences of HO to gain a greater understanding of the clinical needs for this unique patient population. A phenomenological inquiry of five men and one woman selected through purposeful sampling collected in-depth interviews analysed using Colaizzi's method of data analysis. Five emergent themes: (1) Early signs and symptoms, (2) Impact on the rehabilitation journey, (3) The role of the health care professionals (4) Loss of independence and an increased reliance on others and, (5) Learning to live with it: uncertainty, hope and adaptation. Eleven cluster themes were identified, highlighting the meaning of each emergent theme. These findings describe the significant impact the unique symptomology of HO had on the physical and psychosocial functioning of participants throughout the rehabilitation journey. Central to engagement in rehabilitation, is the participants' desire for autonomy particularly in the domains of living independently and community re-integration.

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1. Introduction

Heterotopic Ossification (HO) is a debilitating complication of acute burn and as the survival rates for patients with major burns has increased, so too has the incidence of HO [1,2]. HO has been defined as the production of mature bone in non-skeletal tissue and it remains quite clear that this rare, pathological process is not a trivial complication [3,4]. In the burns population, a challenge exists in the detection of HO in the early stages due to the ambiguity and complexity of patients' signs and symptoms, particularly pain. Although there are a number of risk factors that are considered to relate to the development of HO, the cellular pathways that are most implicated in the formation of pathological ectopic tissue and, the definitive mechanism driving HO development, have not yet been established [5]. Current understanding of the pathophysiology of HO implicates the inflammatory process and systemic responses to trauma as contributors to HO [6]. Burn injury initiates the primary component identified for HO formation, the inflammatory and immune cascade, provoking local tissue disturbance, potentially resulting in heterotopic bone formation [6].

When present, HO can result in a loss of range of motion (ROM), significant pain and discomfort from ankylosed joints, marked muscle weakness and nerve injury causing sensory and motor deficits [7-11]. Such impairments complicate the rehabilitation trajectory for burns survivors and as such, patients experience unique challenges that significantly impact short-term and long-term physical and psychosocial function [9,12,13]. Although research discusses the prevalence of HO in multiple joints of the body, the elbow is the most commonly involved joint [8,12,14]. As many functional tasks depend on movement of the elbow, the impairments in ROM due to stiffness at the elbow, impact on the independence and speed of recovery of the patient [15,16]. In a substantial number of patients, HO can become a prime factor in the inability to perform activities of daily living efficiently [14]. However, there remains a dearth of high-level evidence to drive clinical change in the prevention or treatment of HO in burn patients [17]. It is unclear if, or how exercise therapies should change with clinical suspicion prior to confirmed HO [17]. Indication for drug therapy varies with the stage of the disease, and studies have included prophylactic measures to prevent the formation of ectopic bone [4]. However, while selective NSAIDs hold promise for prevention and treatment, surgery remains the recommended treatment for established HO [17].

A primary goal of burn rehabilitation is the optimal restoration of function and following a major burn quality of life (QoL) is arguably the most important outcome for patients after survival is ensured [7,18,19]. Research discusses a number of influential factors on one's QoL and communicated is; the importance of a person's physical health, their psychological state and personal beliefs, their social relationships and their level of independence [20]. Thus, when the burn trauma itself is compounded by co-existing diagnoses such as HO, this results in poorer short and long-term rehabilitation outcomes.

Burn survivors' experiences of HO provides a unique lens to the rehabilitation challenges of a severe burn [21]. Although

recent findings have vastly improved our understanding of the pathological process and theories regarding surveillance and treatment of HO, to the knowledge of the authors, there is limited research exploring the individual's journey and experience of HO. In alignment with the current scientific rhetoric that stresses the importance of incorporating the perspective of burn survivors in research, information provided by those with first-hand experience has the potential to inform and vastly improve future patient short and, long-term outcomes. Thus, leading to a meaningful enhancement in patient QoL and an improvement in holistic care [22-24]. Consequently, the aim of this descriptive phenomenological study was to gain a greater insight into the 'lived experience' of adult burns survivors diagnosed with HO.

2. Methods

2.1. Design

As a methodology, phenomenology has become widely understood within the domain of qualitative research, and was chosen to provide the theoretical framework for this study [25]. Phenomenology seeks to understand and describe the experience of interest as it is lived, and in particular, descriptive phenomenology endeavours to view the occurrence with fresh eyes, uncontaminated by prior knowledge or scientific impositions [26]. Utilising this methodology the study was designed to provide a valuable and rich understanding of the phenomenon providing insights into the clinical needs of this unique patient subgroup within the burn population [27].

2.2. Ethics

Ethics approval was obtained from the South Metropolitan Health Service (SMHS) and The University of Notre Dame Australia, Human Research Ethics Committees (HREC). Participants were informed that participation was voluntary and that they could withdraw from the study at any time without prejudice. Potential participants were provided, via email, with a participant information sheet and consent form that explained their involvement in the study and the purpose of the research. Each participant provided a signed consent form prior to scheduling and completion of the interview. For analysis and independent review processes, each transcript was de-identified prior to sharing between the researchers.

2.3. Recruitment

Purposeful sampling was used to recruit potential participants for this study. Purposeful sampling was chosen as it remains the dominant sampling strategy for qualitative research allowing selection of participants whose experiences or qualities of the phenomenon facilitate an understanding of the research question [28]. The inclusion criteria specified participants be diagnosed with HO by plain X-ray or other appropriate diagnostic methods, be 18 years of age or greater at time of recruitment, and able to read and speak English so as to impart their experiences and comprehend all necessary

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