

# Roads to recovery: Adult burn survivors' 'lived experience' of rehabilitation

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# PUBLICATIONS AND PRESENTATIONS

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## Publications

Kornhaber, R.A., Abu-Qamar, M. Z., & Wilson, A. (2012). Applying for ethical approval for a national multisite study: the challenges and barriers. *Monash Bioeth Rev*, 30 (1), 103-122.

Kornhaber, R.A., Wilson., A., Abu-Qamar, M.Z & McLean, L. (2013). Burn survivors' personal experiences of rehabilitation: an integrative review. Review submitted.

Kornhaber, R.A., Wilson., A., Abu-Qamar, M.Z & McLean, L. (2013). Coming to terms with it all: Burn survivors' lived experience of acknowledgement and acceptance during rehabilitation. Under review.

Kornhaber, R.A., Wilson., A., Abu-Qamar, M.Z & McLean, L. (2013). The untapped resource of burn survivor peer support: A phenomenological inquiry. Under review.

## Presentations

Coming to terms with it all: Burn survivors' lived experience of acknowledgement and acceptance during rehabilitation. Oral presentation at the Nursing & Midwifery Research & Innovative Practice Conference 2013, Sydney, Australia, 30<sup>th</sup> May 2013.

Burn survivors' personal experiences of rehabilitation: an integrative review. Poster presented at the RNSH UTS USYD KIMR Scientific Research Meeting 2012, Sydney. Australia, 20 - 21 November 2012.

Severe burn injury patients' 'lived experience' of peer support in rehabilitation. Poster presented at the Australian and New Zealand Burn Association Annual Scientific Meeting 2012, Wrestpoint Casino, Hobart, Tasmania, Australia, 9 -12 October 2012.

What's it to you?: Patients' 'lived experience' of compliance with burn care during rehabilitation. Oral presentation presented at the University of Adelaide, Faculty of Health Sciences, School of Nursing Research Conversazione 2012, 'Through the looking glass,' Adelaide, South Australia, 17 - 19 September 2012.

What's it to you?: Patients' 'lived experience' of compliance with burn care during rehabilitation. Poster presented at the University of Adelaide, Faculty of Health Sciences, Postgraduate Research Conference 2012, National Wine Centre, Adelaide, South Australia, 31 August.

Meeting the challenges of research for burns nurses. (invited speaker) Oral presentation presented at Burns Nursing Seminar, InterContinental Hotel, Adelaide, South Australia, 12th May 2012.

Severe burn injury patients' 'lived experience' of peer support in rehabilitation. Poster presented at the RNSH UTS USYD KIMR Scientific Research Meeting 2011, Sydney. Australia, 1 - 2 November 2011.

Severe burn injury patients' lived experience of rehabilitation. Oral presentation presented at the 2nd Nursing and Midwifery Research and Innovative Practice Conference: "Research for Health", Gosford Hospital, Gosford, Australia, 10th May 2011.

Severe burn injury patients' 'lived experience' of rehabilitation: Issues with ethics applications. Oral presentation presented at the University of Adelaide, Faculty of Health Sciences, School of Nursing Research Conversazione 2011, Adelaide, South Australia, April 2011.

Research Proposal: Up out of the ashes: Severe burn injury patients' 'lived experience' of rehabilitation. Oral presentation presented at University of Adelaide, Faculty of Health Sciences, School of Population Health & Clinical Practice, Higher Degree Research Symposium 2010, Adelaide, South Australia, 1 October 2010.

# AWARDS

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Best research paper award, NSLHD Nursing and Midwifery Conference 2013, Sydney, Australia, 30<sup>th</sup> June 2013

Best senior PhD poster award, RNSH UTS USYD KIMR Scientific Research Meeting 2012, Sydney, Australia, 20 - 21 November 2012.

1<sup>st</sup> place prize oral presentation, University of Adelaide, Faculty of Health Sciences, School of Population Health & Clinical Practice, Higher Degree Research Symposium 2010, Adelaide, South Australia, 1 October 2010.

Successful research award recipient of the Royal North Shore Hospital Nursing and Midwifery Resarch Top Up Scholarship, 2012.

Successful research award recipient of the Royal North Shore Hospital Nursing and Midwifery Resarch Top Up Scholarship, 2011.

Successful research award recipient of the Royal North Shore Hospital Nursing and Midwifery Resarch Top Up Scholarship, 2010.

Successful applicant of 2010, Australian Postgraduate Award Scholarship (3 years).

# DECLARATION

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This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

I give consent to this copy of my thesis when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968. I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library catalogue, the Australasian Digital Theses Program (ADTP) and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

Signed:

Dated: 23<sup>rd</sup> of April 2013

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# ABSTRACT

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Since antiquity, the trauma of a severe burn has beset humankind with poor outcomes and survival rates. However, over the last two decades there has been substantial progress in the management of acute burns that has resulted in life expectancy similar to the general population. Despite these advancements in the management of severe burns, the physical, psychosocial and economic implications following a severe burn injury are variable with a lack of substantial progress in the area of burn rehabilitation. Consequently, the rehabilitation of those with severe burns remains a lengthy process with significant associated physical and psychosocial problems. A crucial point raised by burn professionals internationally, is that burn rehabilitation needs to be recognised as a continuum of active care rather than a separate isolated phase, with rehabilitation commencing on the day of injury. The immediate commencement of therapy is a key factor in the management of burns with the initial focus directed towards life support, wound closure, infection control and aggressive metabolic support. However, at some point, patients' rehabilitation needs exceeds those that can be provided by burn units necessitating the transfer to a rehabilitation facility. Therefore, it is the experiences of these patients rehabilitating from severe burns that are the focus of this study.

This thesis reports on a research undertaking that explores patients' 'lived experience' of rehabilitation after a severe burn injury. The study utilised a descriptive phenomenological methodology approach. Purposeful sampling was utilised to select participants who sustained severe burns that required intensive rehabilitation across three Australian states. The researcher interviewed 21 burn survivors utilising semi structured interviews that were digitally audio recorded. The interviews were transcribed verbatim then analysed using Colaizzi's method of data analysis. From the data analysis, 25 cluster themes developed from the participants' experiences which were further merged into seven emergent themes that structured the 'lived experience' of burn survivors' rehabilitation journey forming the basis of the findings reported. The essence of these experiences is reflected in these themes: *Vital supports, Spatial environment, Endurance, Acceptance, Impact, Challenges and Progression*. These emergent themes incorporate both the physical and psychosocial impact after a severe burn injury.

Central to burn rehabilitation is the notion of social support that has a significant influence on burn survivors' psychosocial rehabilitation. Fundamental to burn rehabilitation are the development of coping strategies and the means of adjusting and adapting. Patient centred goals provided the necessary motivation and tenacity to progress through the lengthy rehabilitation journey that besets those with severe burns. Acceptance of an altered self-image and body image is a slow and challenging experience for those with severe burns. Key to burn rehabilitation is the appropriate timing and delivery of burn therapy and education that facilitates patients' adherence to burn care and therapy. The process of transition and reintegration after a severe burn injury is a significant event in the rehabilitation of burn survivors. Access to ongoing rehabilitation services remains a challenging experience because of the lack of burn expertise in the community setting.

This study has unearthed fundamental aspects of burn rehabilitation that span across a diverse and multidisciplinary sector of healthcare. In essence, these findings may provide for the further development of health policy in relation to management of severe burn injury; principles and guidelines for best practice; and both survivor and health professional education so as to improve outcomes for burn survivors, their families and the community .