

School of Public Health

**An Exploratory Study of the Impact of Scarring on Sexuality
and Body Image of Females Who Have Sustained a Burn
Injury**

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**This Thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University**

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Declaration

This thesis contains no material, which has been accepted for the award of any other degree or diploma in any university. To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

The work described in this thesis is the original work of the author and was undertaken solely by the author. The work of study design, ethics approval, writing of the thesis and published papers was undertaken with the primary supervision of Professor Rosemary Coates, Associate Professor Maryanne Doherty and Winthrop Professor Fiona Wood. The data analysis was undertaken with assistance from Michael Phillips.

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Abstract

Background: There is growing evidence to suggest that following the acute phase of rehabilitation, body image and sexuality become the prime predictors of psychological function post-burn injury, particularly in females.

The purpose of this study was to improve clinical outcomes for female burn survivors by i) exploring the extent to which disfiguring trauma impacts on sexuality and body image and interpersonal relationships in females, ii) to identify how these issues are currently being addressed in burn rehabilitation and iii) advocate for the inclusion of sexuality issues as a matter of discourse within burn trauma clinical settings.

Methods: A sequential, mixed methods research design was used to identify potential correlations between the incidence of poor sexual esteem, sexual avoidance and satisfaction with life and increased body image dissatisfaction in female burn survivors. Semi-structured interviews incorporated in this study aimed to provide the lived experience of changes to individuals' sexuality and body image as well as their perceptions of the inclusion of sexuality in the current rehabilitation setting.

Results: Female burn survivors are particularly at risk of sexuality and body image dissatisfaction post injury. These changes are potentially long standing and independent of improvements in physical function.

Conclusions: Sexuality and body image changes post-burn injuries are significant issues that should be addressed as a matter of discourse within burn rehabilitation. Moreover, when screened appropriately, these two issues in combination have a potentially unique and important role in the identification of overall quality of life for burn injury survivors.

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I dedicate this thesis to
Grant Connell
who was unfailing in his
love and support

I would also like to dedicate this thesis to
survivors of burn injuries.

I hope the this study helps contribute
to improving services and in turn the quality of life
for you all.

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Abbreviations

ADL:	Activities of daily living
BCORP:	Burns Clinical Outcomes Research Project
BDI:	Beck Depression Inventory
BES:	Body Esteem Scale
BID:	Body Image Dissatisfaction
BMSFI:	The Brief Male Sexual Function Inventory
BSHS-B:	Burns Specific Health Scale Brief
BSSC:	Brief Sexual Symptom Checklist
CBT:	Cognitive Behavioural Therapy
DFSI:	The Derogatis Sexual Functioning Inventory
Ex-PLISSIT:	Explicit-Permission, Limited Information, Specific Suggestions, Intensive Therapy
FSFI:	Female Sexual Function Index
ICSM:	International Consultation in Sexual Medicine
IIEF:	International Index of Erectile Function
MBSRQ-IA:	The Multi-dimensional Body-Self Relations Questionnaire
MMR:	Mixed Methods Research
OT:	Occupational Therapist
Physio:	Physiotherapist
PLISSIT:	Permission, Limited Information, Specific Suggestions, Intensive Therapy
PROMIS[®]SexFS:	PROMIS [®] Sexual Function and Satisfaction Measures Brief Profile
PTSD:	Post Traumatic Stress Disorder
QoL:	Quality of Life
QUAL:	Qualitative Research
QUAN:	Quantitative Research
RPH:	Royal Perth Hospital
SCI:	Spinal Cord Injury
SCS:	Sexual Complaints Screener
SMM:	Sequential Mixed Methods Research

SSS-W:	Sexual Satisfaction Scale for Women
SWAP:	Satisfaction with Appearance Scale
TBI:	Traumatic Brain Injury
TBSA:	Total Body Surface Area
WA:	Western Australia
WHO:	World Health Organisation
WHODAS II:	World Health Organization Disability Assessment Schedule II

Glossary of Terms

Cognitive Genital Disassociation: The process of “shutting out” sexuality following a trauma injury

Sexual Disenfranchisement: Disconnection and/or disappointment with engagement with sexual activities following a trauma injury

Sexual Rediscovery: Reconnection with ones sexuality following a trauma injury. Characterised by renewed sexual interest and exploration.

SF:36: SF:36® Health Survey, validated self-administered questionnaire measuring health related quality of life.

Chapter 1: Introduction

1.1 Statement of the Problem

Significant improvements in survival rates of individuals who sustain a life threatening physical injuries such as burns have resulted through the advancements in medical technology.¹⁻⁵ In the past medical focus has been orientated toward patient outcomes measured in terms of mortality and morbidity,^{1, 3-5} however focus is now shifting towards rehabilitation outcomes being measured in terms of quality of life (QoL) for the survivors.^{1, 6} Whilst definitions of quality of life include aspects of sexuality, current healthcare services fall short of including sexuality as a matter of discourse.⁷ For the purpose of this research the World Health Organisations⁸ working definition of sexuality is used as a frame of reference when discussing sexuality issues:

“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors.” (WHO, 2006)

Literature regarding the impact of scarring on individuals sexuality and relationship development is limited and contradictory. Several studies have indicated against popular thought that there is no correlation between the severity of a burn injury on sexual-esteem, sexual depression and sexual behaviour.^{1, 8-11} Studies by Orr, Reznikoff and Smith,⁹ and Tudahl, Blades and Munster¹⁰ both found that whilst there was no direct correlation between total body surface area (TBSA) of burn injuries and issues of sexuality, this correlation become significant when analysed according to gender. In both studies strong correlations were found between females and

negative body image, indicating that females may experience less sexual satisfaction post-burn injury than males, with higher incidents of depression and lower self-esteem. These findings are consistent with research into weight loss disorders, whereby the impact of perceived beauty on females results in increases of low self-esteem and food risk behaviours in female adolescents as opposed to male adolescents.¹²⁻¹⁴

Abdullah, Blakeney, Hunt, Broemeling, Phillips, Herndon's,¹⁵ investigation of the impact of visible scars on self-esteem in paediatric patients, found that the more visible the scar the higher the chance that the individual would have negative body image, decreased happiness and satisfaction with life. Conversely to the studies of Orr, Reznikoff and Smith⁹ and Tudahl, Blades and Munster,¹⁰ the correlation was stronger in male participants than female. In addition, it was found that those who had the greatest amount of scarring scored lower in the scales for "physical appearance", "happiness" and "satisfaction".

The contradictory evidence relating to the extent to which scarring impacts body image and self-esteem and perceived attractiveness, highlights the fact that there is insufficient literature regarding sexuality in burn populations. In essence there is still more that we need to learn in order to improve services for survivors.

Burn related literature acknowledges that body image, sexuality and interpersonal relationships are important psychosocial factors that should be addressed within burn rehabilitation programmes.^{6, 16-19} Fauerbach¹⁹ further suggests that severe psychological stress is among the most prevalent, enduring and imitating secondary complications following a burn injury. This psychological stress frequently manifests as depression,^{1, 20} body-image dissatisfaction,^{3, 21} social avoidance^{3, 22} or post-traumatic stress disorder (PTSD).^{18, 20} The longitudinal study by Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach²³ determined that body image satisfaction was the most important determinant of overall psychosocial function one year post-burn injury. The degree to which individuals place the importance of personal physical appearance, directly impacts the severity of body image dissatisfaction. This finding was particularly prevalent for female participants.

Body image has been defined as the mental picture one has of his/her body.^{24, 25} This mental picture is influenced by one's attitude towards the perception of the physical self, appearance, health, wholeness, functioning within cultural norms and

sexuality.²⁴ There is a dearth of information regarding the impact of disfiguring trauma on body image and sexuality in burn survivors. Literature regarding body image is predominantly based on studies of weightloss disorders and women with breast cancer who have undergone mastectomies. Results of the Pikler and Winterowd's²⁶ study of women diagnosed with breast cancer, indicated that participants with better body image, in turn coped better with adjustment to their cancer diagnosis. Negative self-perceptions of body image lead to greater dissatisfaction with physical appearance, reluctance to look at one's self naked, perceived loss of femininity, feeling sexually unattractive and general dissatisfaction with their surgical scars. Wilmoth²⁷ describes a concept of breast cancer survivors 'feeling less than a woman'. In this study Wilmoth²⁷ states that a woman's sense of self is based upon feedback that is internalised about her breasts, menstruation and being able to engage comfortably in sexual activity. Whilst breast cancer and burns survivors are different diagnostic groups, there are some potential valuable insights that can be gained through breast cancer research regarding body image and sexuality, particularly as mastectomies have been described as a form of amputation and disfigurement that effect body image and sexual relations.²⁸ One could argue that disfigurement and/or amputation associated with breast cancer is similar to the disfiguring injuries associated with burns, thus an appropriate comparison to gain further understandings.

Without question there is the need for further empirical research regarding quality of life including sexuality following a burn injury.^{1, 11, 15, 18} Thombs, Haines, Bresnick, Magyar-Russell, Fauerbach and Spence²⁹ believe that the most important predictor of overall psychological function at one year post-burn is body image satisfaction/distress, particularly for females. This thesis investigating sexuality and body image in females who have sustained a burn injury, will therefore add valuable understanding to a limited body of knowledge that could bring about positive changes in how we look at burn rehabilitation.

1.2 Research Question

This research aimed to answer the question:

“How does scarring differentially affect sexuality, body image and interpersonal relationships in females who have sustained a burn injury?”

1.3 Research Aim and Objectives

The aim of this research was to explore the extent to which trauma impacts sexuality and quality of life outcomes in female burn injury survivors.

Through analysis of SMM research data collected throughout this research the following objectives of this research were met:

1. To explore the extent to which scarring impacts differentially on sexuality, body image and interpersonal relationships in females post-burn injury
2. To identify how sexuality is currently addressed within rehabilitation services
3. To justify the inclusion of sexuality as a matter of discourse within rehabilitation settings

1.4 Ethics Process

Approvals for this study were gained from Curtin University Human Research Ethics Committee, approval code HR/196/2008 (Appendix B). To enable the research to be conducted with current Royal Perth Hospital patients and datasets, additional ethical approval was gained from the Royal Perth Hospital Ethics Committee, approval code EC 2009/108 (Appendix B). The Patient Information Sheet (Appendix C) and Patients Consent Sheet (Appendix D) that were approved as part of the ethical processes are supplied in the appendices section of this thesis.

1.5 Significance of the Study

It is anticipated that this study will be of international significance not only to burn rehabilitation programmes, but to any rehabilitation services for survivors of significant physical and/or disfiguring injuries.

There are few studies related to female sexuality and body image post injury. This study provides important data regarding the impact of disfigurement on sexuality and body image which up until now has been mainly focussed on female weight loss issues and breast cancer survival.

1.6 Limitations of the Study

Each strand of study presented in this thesis consists of an independent piece of research with its own study design, methodology, discussion and conclusions.

More in-depth discussions regarding the limitations of each strand of study are provided within the discussion sections of chapters 3-7 of this thesis.

The main limitation throughout the Quantitative (QUAN) phases of research was the issue of dealing with outlier responses. In the Connell, Coates and Wood's⁶ article presented in chapter 5 outlier responses were considered. Due to the number of variables and the adjustments made to the 'burnsite' categories to deal with these variables for the statistical analysis, we were unable to accurately identify and plot the impact of outlier responses. Initial indications of this data suggest that outlier responses did not greatly impact the results. Whilst this is a limitation within the data analysis, this study has highlighted that this is an important consideration thus a further multivariate statistical analysis was conducted and is presented as the Connell, Phillips, Coates, Doherty-Poirier and Wood¹⁷ publication presented in chapter 6. In the Connell, Phillips et al¹⁷ analysis of BSHS-B outcome measures not all patients completed BSHS-B questionnaires at all time points for this study. This potentially presented some potential issues regarding missing data. This was not deemed by the authors as a significant issue the missing observations accounted for less than 5% of the data. The missing data, therefore, was unlikely produce a major selection bias for this study.

Lastly with regard to the Qualitative (QUAL) strand of this research design, the main limitation was the small sample size of participants. Due to the sensitive subject matter of the interviews, difficulty was experienced getting women to consent to being involved in this phase of research. Only 5 participants were interviewed, however, these participants represented the range of burn survivors that are treated at the Western Australian (WA) Burns Unit in terms of variety of burn size, location and time post-burn. Although the sample size was smaller than anticipated, it is believed that this study adds valuable insights regarding the lived experience of female burn survivors. This is important information of which there is currently very little published.

1.7 Thesis Organisation

This thesis is presented as a series of published papers that represent each strand of the study. Chapters 3-7 are original copies of the text from each published paper. Publisher copyright information and permissions are provided in Appendices E-I. The following is an outline of the list of published papers associated with this thesis and the aims and/or objectives each paper addresses.

Connell, K.M., Coates, R., Wood, F.M. (2014). Sexuality following trauma injury: A literature review. *J Burns & Trauma*, 2(2), 62-70.

- To identify the experiences of adult trauma survivors regarding how changes with regard to sexuality and body image impact QoL

Connell, K., Coates, R., Doherty, M., Wood, F. (2013). A literature review to determine the impact of sexuality and body image changes following burn injuries. *J Sex Disabil*, 31(4), 403-412.

- To determine the impact of sexuality and body image changes following burn injuries for adult burn survivors
- Identify if there is a relationship between sexuality and body image and the impact that this has on survivors QoL

Connell, K.M., Coates, R., Wood, F.M. (2012). Sexuality following burn injuries: A preliminary study. *J Burn Care Res*, 34(5), e282-e289.

- To determine if WA burn survivors' report negative changes regarding their sexuality and body image post-burn injury
- To determine if females are more susceptible to these changes

Connell, K.M, Phillips, M., Coates, R., Doherty-Poirier, M., Wood, F.M. (2014 in press). Sexuality, body image and relationships following burns: Analysis of BSHS-B outcome measures. *Burns*

- To determine the variables that contribute to females reporting negative changes to their sexuality and body image satisfaction post-burn injury

Connell, K.M., Coates, R., Wood, F.M. (2014 in press). Burn injuries lead to behavioural changes that impact engagement in sexual and social activities in females. *J Sex Disabil.*

- To investigate the lived experience of female burn survivors with regard to sexuality and body image changes that they experience post-burn injury
- To investigate how sexuality and body image issues are currently addressed in the WA burn service, and provide recommendations for future service provision.

The final Chapter of this thesis acts as an exegesis, bringing together all the evidence from the five strands of research investigation. Final conclusions and recommendations for future research directions and clinical practice are provided.

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Chapter 2: Methodology

2.1. Chapter Introduction

This chapter provides a discussion of the methodological approach employed for this research. A sequential, mixed methods design was chosen as the conceptual framework of this research as this allowed for the investigation of causal relationships among female sexuality and body image changes to be validated through observations and analysis of the ‘lived experiences’ of female burn survivors.¹ This chapter presents the conceptual framework utilised to guide the research, the results section discusses the findings and inferences that arose during the course of the research.

2.2. Mixed Methods Design – A Research Approach

There has been a shift in health related research to view the incorporation of both QUAN and QUAL methods to form a mixed methods (MM) research design, with the view that a MM approach provides greater understandings of the research phenomena combined, as opposed to using one method alone.¹⁻⁵ Where QUAN research can be seen as lacking the understanding of the ‘lived experience’ in terms of the context in which participants’ experience the phenomena in question, QUAL research provides understanding of the potential ‘lived experience’ of an individual or small sample group.^{2-4, 6} In contrast, QUAL research is often criticised as an inferior research methodology compared with QUAN, as the data and is perceived as being more open to the interpretation of the researcher, which in turn lends itself to greater bias.^{2, 6} In addition, there are often difficulties generalising QUAL findings to larger study populations due to smaller sample sizes generally utilized; and to a lack of formal statistical predictive evidence, compared to those achieved through QUAN data analysis techniques.^{2, 6} MMR overcomes many of the limitations presented by using either QUAN or QUAL research methods in isolation, in that it provides more comprehensive data collection and analytic tools appropriate to both research methods.²⁻⁷

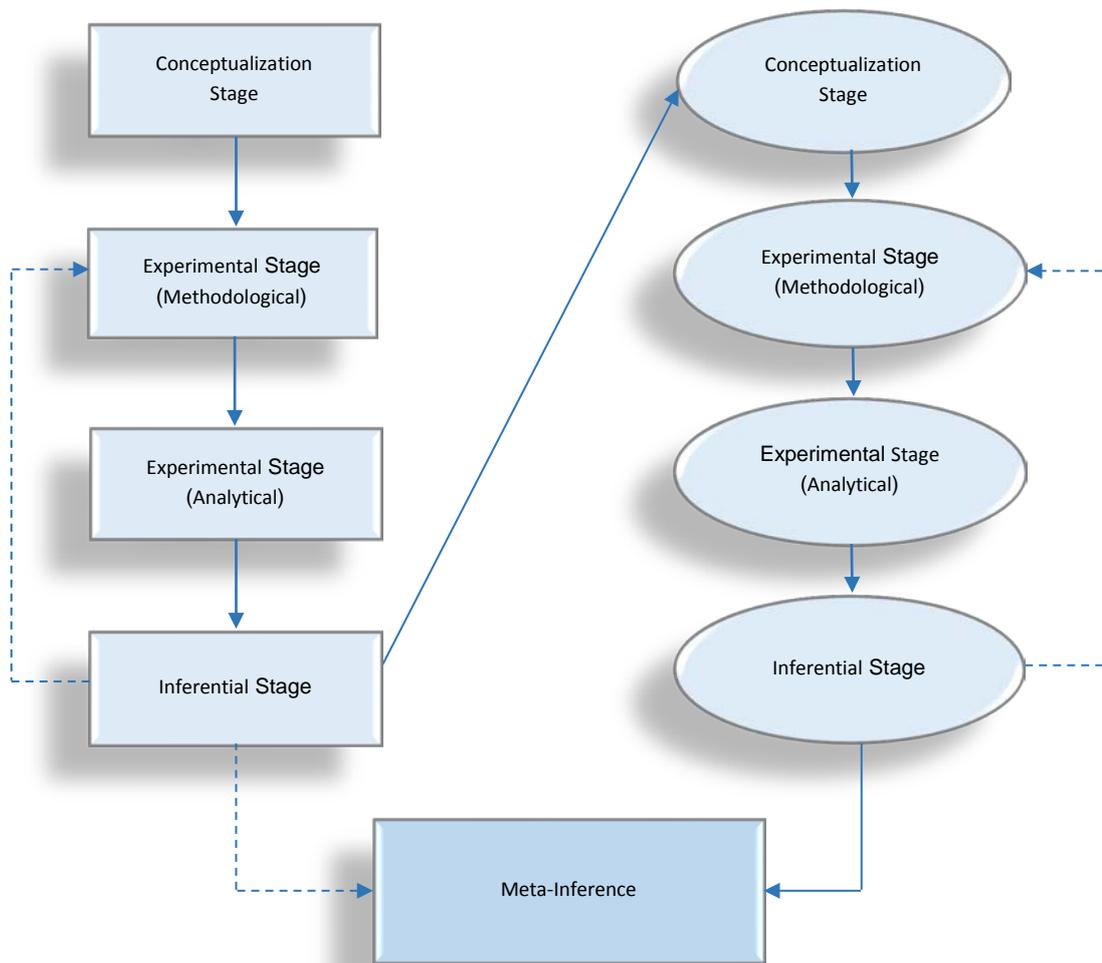
MM research is guided by philosophical assumptions as well the modes of methodological data inquiry.^{2-4, 8} This in turn shapes the use of QUAL and QUAN

research methods to be used during the phases of the research process. Others describe the methodology of MM research as the mediator that acts to integrate the conceptual and methodological issues within the research design.⁴ As a method MM research focuses on collecting data from both QUAL and QUAN approaches from either a single study or from a series of studies.^{2-4, 6, 9} The incorporation of QUAL and QUAN data occurs with the interpretation of results during the data analysis phases.¹ The overarching premise of MM is that the combination of the use of both QUAL and QUAN research methodologies provides a greater understanding of the research phenomena, rather than using either approach alone.^{2-5, 7-9}

2.3 Sequential Mixed Methods Research Design

This research was developed using a sequential mixed model design approach, as described by Teddlie and Tashakori (Figure 2.1).³ Sequential mixed methods (SMM) research designs are a type of MM design, the differentiation being that with SMM at least two strands of QUAL and QUAN research are conducted chronologically.³ In SMM design research, questions for each strand of the study are generated from the inferences that emerge from the previous strand of data.^{4, 10} Andrew and Halcomb¹¹ state that the complex health issues associated with contemporary health care research require a multifaceted approach. They conclude that MM research designs afford health care researchers with diversity, versatility and creativity when approaching a research problem, which can lead to a comprehensive understanding of the health issue in question. Due to the complex interplay of physical and psychological health issues related to sexuality and body image changes in burn survivors, a SMM approach was deemed appropriate to explore and confirm questions in a structured, chronological way.³

Figure 2.1: Sequential Mixed Model Design⁴



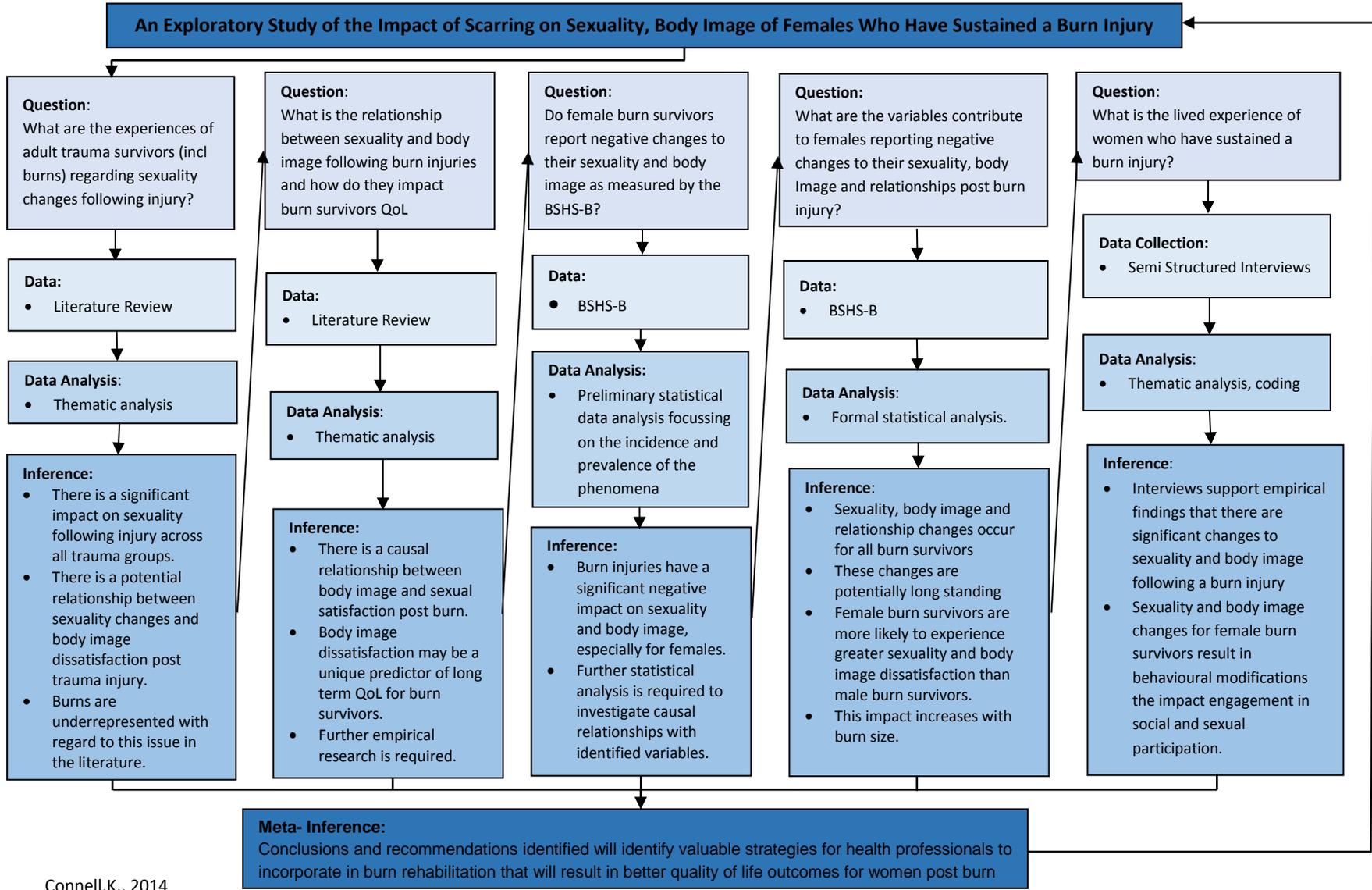
Tashakkori A, Teddlie C. *Mixed Methods in Social and Behavioural Research*.

Thousand Oaks: Sage Publications; 2010.p 154.

2.4 Sequential Mixed Methods Design Applied to this Study

SMM research design was used for explanatory purposes with regard this study.^{2, 9, 12} QUAL methods followed QUAN survey analyses to better understand the experience of burn survivors and to validate the QUAN findings.⁹ Analysis of QUAN data strands of this research were used to extrapolate predictive inferences that were explored in depth using phenomenology based QUAL data collection and analysis methods. This research design is considered sequential, as each strand was conducted consecutively with the inferences formed by the each strand results, shaping the research question and design of the following strand. All phases of data analysis have been incorporated in a meta-analysis that forms the concluding chapter of this thesis. The SMM strands applied to this research are outlined in Figure 2.2

Figure 2.2: Sequential Mixed Methods Design Applied to this Study



2.4.1 Strand One:

A literature review formed the first strand of this research. The aim of this strand was to provide a background investigation of the impact of trauma injuries on sexuality for survivors post injury. Three trauma groups selected were; spinal cord injury (SCI), traumatic brain injury (TBI) and burns, as they represented the most common trauma diagnoses. Commonalities with regard to the physical and psychological impact of trauma on sexuality and relationships were found across all trauma groups. This literature review did highlight a significant disparity in sexuality research between the trauma groups with 25 articles meeting the inclusion criteria for SCI and only 6 being included for TBI and 5 for burn injuries.¹³

The inference from this study was that trauma injury has a significant impact on sexuality, which is not readily addressed by rehabilitation services. Additionally there appeared to be a strong link between sexuality changes and body image dissatisfaction which required further investigation in the burn population.

This strand of research has been published in the *Journal of Burns & Trauma*. The study design, methodology, results and conclusions are provided in chapter 3 of this thesis.

2.4.2 Strand Two:

The second research strand involved a secondary literature review investigating the impact of burn trauma on sexuality and body image changes post injury. The purpose of the study two fold. Firstly it aimed to determine the impact of sexuality and body changes in the adult burn population, particularly with regard to females, and secondly is aimed to identify if there were any causal relationships between these two variables.

The inference from the results of this study was that burn injuries result in changes in body image and sexuality that negatively impact the quality of life of survivors. This finding supported the inclusion of a preliminary data analysis outcome measures collected at the Royal Perth Hospital Burn Service, to identify if this was a potential phenomenon for WA burn survivors, which has not been investigated before.

This strand of the research has been published in the *Journal of Sexuality and Disability*. The study design, methodology, results and conclusions are provided in chapter 4 of this thesis.

2.4.3 Strand Three:

A preliminary QUAN analysis of the Burns Specific Health Scale Brief (BSHS-B) questionnaire (Appendix A), collected via the Burn Clinical Outcomes Research Project (BCORP), was conducted to investigate the potential incidence and prevalence of sexuality and body images changes in the WA burn population. BCORP data collection has been ongoing since 2005. At the time of this phase of the research outcome data had been collected from 362 patients.

The BSHS-B is a validated measure administered as part of BCORP as an indicator of potential health related quality of life (QoL) issues for rehabilitation regarding physical and physiological function. Additionally, the BSHS-B incorporates specific questions relating to sexuality, body image and relationships.

BSHS-B questionnaires were analysed to gain an overall sense of the potential incidence and prevalence of the burn survivors reporting negative changes to their sexuality, body image and relationships over a 12 month period. This study was published in the Journal of Burn Care & research. The study design, methodology, results and conclusions are provided in chapter 5 of this thesis.

The inference from this preliminary study indicated that there were potentially long standing issues regarding sexuality and body image changes for burn survivors which warranted further multivariate statistical analysis.

2.4.4 Strand Four:

Results from strand three indicated that burn injuries have a significant negative impact on sexuality and body image satisfaction for burn survivors. In support of the overarching hypothesis of this research, high rates of body image dissatisfaction were found, particularly for female burn survivors.

This strand of the research specifically focussed on expanding upon the previous QUAN preliminary study. As this study was conducted sequentially, further BSHS-B data sets had been gathered and were available for analysis, thus a greater number of respondents were incorporated in this data analysis. This allowed for further formal multivariate statistical data analysis to be used to identify potential predictive

correlations regarding burn injuries and decreases in sexual, body image and relationship esteem.

This strand of research was published in the Burns Journal. The study design, methodology, results and conclusions are provided in chapter 6 of this thesis.

2.4.5 Strand Five:

This QUAL strand of the research was based upon using information gained from the QUAN stages of the data collection and analysis to guide QUAL person-to-person semi-structured interviews of female burn survivors. This strand of the research was aimed at gaining an understanding of the ‘lived experience’⁷ of female burn survivors including their views of the current inclusion of sexuality and body image issues in rehabilitation.

Questions for the semi-structured interviews were based on the themes identified from the previous QUAN data strands of analysis. As semi-structured interviews are a dynamic process this allowed the researcher freedom to add questions and respond to issues raised, to validate the information gained and reflect the ways participants understand the experience of the phenomena of sexuality and body image changes post-burn injury.

This strand of research has been submitted for publication in the Journal of Sexuality and Disability. The study design, methodology, results and conclusions are provided in chapter 7 of this thesis.

2.4.6 Strand Six:

A final meta-inference and discussion acts as an exegesis of this research and is provided in chapter 8. This chapter is based upon bringing together the combination of both the QUAN and QUAL data gathered in all of the strands of study.

Along with the overall conclusions, recommendations for changes to clinical practice and future research are provided.

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Chapter 3: Sexuality Following Trauma Injury: A Literature Review

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3.1 Chapter Introduction

This chapter is a post-print version of the above article published in the journal of *Burns & Trauma*. Publisher copyright policies relating to this article are supplied in Appendix E. Co-author statements are provided in Appendix J.

The aim of this strand of research was to provide initial background information on the impact of trauma injuries on sexuality post injury. The objective was to identify the experiences of adult trauma survivors with regard to how their trauma injuries impact changes to their sexuality and body image.

Trauma groups, other than burns, were included in this review to investigate this issue from the perspective of burns being a subgroup of trauma injuries as a whole.

3.2 Abstract

Restoration of the quality of life (QoL) of trauma injury survivors is the aim of trauma rehabilitation. It is generally acknowledged that sexuality is an important component of QoL, however, rehabilitation services frequently fall short of including sexuality as a matter of routine discourse. This review investigates literature relating to three trauma groups; SCI, TBI and burns. The aim was to investigate the experiences of trauma survivors regarding how sexuality changes following a trauma injury impacted their QoL to identify future research directions, and to advocate for the inclusion of sexuality issues within trauma rehabilitation services.

Five databases were searched: Proquest, Ovid, Cinahl, Medline, PsycInfo and Cochrane Central Register of controlled trials.

A total of 36 eligible studies were included: SCI (n=25), TBI (n=6) Burns (n=5).

Four themes were identified across the three trauma groups which were labelled; physiological impact of trauma on sexuality, cognitive-genital dissociation, sexual disenfranchisement and sexual rediscovery.

Trauma injury has a significant impact on sexuality, which is not routinely addressed within rehabilitation services. Further sexuality research is required amongst all trauma groups to improve rehabilitation services and in turn QoL outcomes for all trauma survivors.

3.3 Introduction

Improved rate of survival post trauma has precipitated a shift from outcomes measured in terms of mortality, to outcomes being measured in terms of activities of daily living (ADLs) and quality of life (QoL).^{1, 2}

Sexuality is a component of many of the QoL domains, however, current QoL measures do not adequately incorporate sexuality within their assessment components, thus perpetuate the exclusion of sexuality as a matter of discourse within trauma rehabilitation.³

The incidence and prevalence of sexuality issues for trauma survivors is impossible to estimate due to a lack of consistency within sexuality research with regard to sexuality domain definitions, data collection methods and measurement tools.

Phelps, Albo, Dunn and Joseph's⁴ study of married or partnered men with a spinal cord injury (SCI) suggested that whilst 96% of participants were sexually active, 20% reported little to no sexual desire and 44% reported dissatisfaction or indifference with their sexual relationship. Mendes, Cardoso and Savall⁵ in reference to the findings of their study of sexual satisfaction in men with SCI, found that the majority of their participants (60%) were satisfied with their sexual lives. However, their findings did indicate that there was a significant fall in sexual satisfaction in following SCI with 80% (32 men) in the pre-lesion period of the study reporting to be very satisfied with this percentage dropping to 47.5% (19 men) in the post-lesion study period. There has been little empirical research conducted regarding female sexuality following SCI. Kettl, Zarefoss, Jacoby, Garman, Hulse, Rowley's⁶ study of female sexuality following SCI found that 26% of participants rated sex as less important following injury and 23% were less satisfied with their sexual lives. Most significantly, this study found that the majority of women experienced body image changes with 52% reporting that their bodies were less attractive than they were before their SCI. The authors suggest that these body image changes may play a role in both the reduction of sexual activity and enjoyment found in the results of this study.

Changes to sexual functioning have also been documented following brain injury. Kreuter, Dahllof, Gudjonsson, Sullivan and Siosteen⁷ study of males and females post traumatic brain injury (TBI) 56% of the participants (N=92) reported dissatisfaction with the frequency of sexual activity with 31% identifying a lack of

intimate partner being the main contributing factor. In contrast 86% of the respondents who had an intimate partner were satisfied with their sexual lives and 75% were satisfied with the frequency of intercourse. Ponsford⁸ study also supports these findings with 54% of participants (N=280) reporting a decrease in sexual frequency. In addition, 41% expressed a decrease in sexual drive, 39% felt the ability to satisfy their partner had decreased, 38% had a decreased ability to engage in sexual intercourse and 38% reported less enjoyment in sexual activity. The author concludes that more than 50% of people following a TBI experience significant sexual changes up to 5 years post injury.

There has been very little research regarding sexuality following burn injuries, thus research involving adequate methods and sample sizes are scarce. Evidence from a Western Australian burn unit sample suggests that burn injuries have a significant impact on sexuality and body image satisfaction and that these changes are potentially long standing.^{9,10} Our preliminary data analysis of responses from the Burns Specific Health Scale- Brief, suggests that over 20% of burn survivors (N=362) report a loss of sexual interest up to 12months post injury. Body image dissatisfaction is high amongst burn survivors with over 40% indicating the perception that there is unattractive to others and 40% indicating that their scars bother them. A significant finding, was that the severity of the responses, as scored via a Likert scale, were much higher in females especially for the body image domains. We concluded that sexuality and body image may have a role in post-burn psychosocial adjustment and quality of life that requires further research.

Sexuality is a dynamic entity in which the interplay of biological, psychological, sociological, spiritual and cultural factors influence personality development, sense of self-esteem and ability to form interpersonal relationships^{11,12}. In order to conceptualise the dynamics involved, the World Health Organisation (2002) working definition of sexuality¹³ will be used as a frame of reference when using the term sexuality throughout this review.

The research question guiding this literature review was: What are the experiences of adult trauma survivors regarding how changes in their sexuality impact their QoL? Spinal cord injury (SCI), Traumatic brain injury (TBI) and burn trauma groups were chosen for this review on the basis that they represented common trauma diagnoses and provided a wide range of biopsychosocial rehabilitation issues in which to compare.

3.4 Methods

3.4.1 Search Strategy

A search was conducted up to March 2013 using Proquest, Ovid, Cinahl, Pubmed and Medline databases. Spinal cord injury(s), traumatic brain injury(s), acquired brain injury, burn(s), disfiguring scarring, where used as the free text word searched with sex*, sexual*, sexual adjustment, sexual satisfaction and sexual rehabilitation as keywords.

3.4.2 Eligibility Criteria

Research articles published between January 1990 and January 2013 pertaining to sexuality following SCI, TBI and burn(s) were included within this review, to look at current issues in sexual rehabilitation.

Both quantitative (QUAN) studies that evaluated sexual changes through outcome measures and qualitative (QUAL) studies that investigated the 'lived experience' of sexuality changes in adult trauma survivors were included in this review.

Research articles were included if they described research in which sexuality of the individual trauma groups was investigated. Case studies were initially excluded from the eligibility criteria, as they provided anecdotal information only. However, due to low numbers of research articles regarding sexuality following burns and TBI's compared with SCI literature, they were subsequently included for these two trauma groups, to provide potential insight regarding sexuality issues to compare with the SCI literature.

3.4.3 Exclusions

Reviews, opinion pieces, expert opinions and papers that did not deal specifically with the three trauma groups were excluded. Research articles focusing solely on the physiological aspects of sexual function were eliminated, however, research regarding sexual functioning which encompassed the broader aspects of sexuality as outlined by the WHO (2002) working definition of sexuality¹³ were included.

3.4.4 Data Abstraction

In order to analyse qualitative data within the literature themes were identified and labelled to attribute meaning to phenomena¹⁴. Themes were further refined according to the importance of the theme based upon the frequency that the phenomena appeared throughout the literature; the significance of the phenomena as identified by the research articles; and the theme's pervasiveness across the trauma groups selected for review and their rehabilitation services.¹⁵

A phenomenological study conducted by Tepper, Whipple, Richards and Komisaruk¹⁶ of sexual experiences of women following SCI identified common post injury psychosocial phenomena which were grouped and labelled; 'cognitive-genital dissociation', 'sexual disenfranchisement' and 'sexual rediscovery'. These labels were used as they were relevant to understanding the psychosocial components of the body of literature reviewed in relation to sexuality post-burn, TBI and SCI trauma groups, as opposed to SCI alone. In addition to these three themes a fourth theme emerged regarding the physiological impact of trauma on sexuality, and thus is also included in this review.

3.5 Results

Publication titles and abstracts were reviewed online. A total of 36 eligible studies were identified for review: SCI (n=25), TBI (n=6) Burns (n=5) (Table 3.1).

Table 3.1: Articles Included in Sexuality Following Trauma Injury Review

Author(s)	Title	Participants (N=)	Methods	Sexuality Issues Addressed
SCI Articles				
Anderson et al (2007)	Spinal cord injury influences psychogenic as well as physical components of female sexuality	87 (f)	General questionnaire*	Sexual response Sexual satisfaction
Anderson et al (2007)	Long-term effects of spinal cord injury on sexual function in men: Implications for neuroplasticity	199 (m)	General questionnaire*	Sexual response Sexual satisfaction
Cardoso et al (2008)	Self-awareness of the male sexual response after spinal cord injury	90 (m)	General questionnaire *	Sexual response
Ferreiro-Velasco et al (2005)	Sexual issues in a sample of women with spinal cord injury	37 (f)	Semi structured interview	Sexual response Sexual satisfaction Sexuality & rehabilitation
Fisher et al (2002)	Sexual health after spinal cord injury: A longitudinal study	32 (m) 8 (f)	The Sexual Health Needs Survey *	Sexual activity Sexual adjustment Sexual satisfaction Sexuality & rehabilitation

Forsythe and Horsewell (2006)	Sexual rehabilitation of women with a spinal cord injury	70 (f)	Discussions from workshops	Sexuality & rehabilitation
Hess et al (2007)	The experience of four individuals with paraplegia enrolled in an outpatient interdisciplinary sexuality program	4 (m)	Sexual History Questionnaire *	Sexuality & rehabilitation
Ketttl et al (1991)	Female sexuality after spinal cord injury	27 (f)	Descriptive questionnaire *	Sexual satisfaction Sexual response Sexuality & rehabilitation
Kreuter et al (2008)	Sexuality and sexual life in women with spinal cord injury: A controlled study	532 (f)	Spinal Cord Injury Women Questionnaire*	Sexual activity Sexual response Sexuality & rehabilitation
Kreuter et al (1996)	Sexual adjustment and quality of relationships in spinal paraplegia: A controlled study	64 (m) 11 (f)	Relationship questionnaire* Quality of Life Visual analogue Hospital Anxiety and Depression Scale (HAD)	Sexual activity Sexual response Sexual satisfaction
Leibowitz (2005)	Sexual rehabilitation	24 (f)	Semi structured interviews	Sexual activity Sexuality &

	services after spinal cord injury: What do women want?			rehabilitation
Leibowitz and Stanton (2007)	Sexuality after spinal cord injury: A conceptual model	24 (f)	Semi structured interviews	Sexual activity Sexual response Sexuality & rehabilitation
Lysberg and Severinsson (2003)	Spinal cord injured women's views of sexuality: A Norwegian survey	48 (f)	Descriptive questionnaire *	Sexual satisfaction
Mendes et al (2008)	Sexual satisfaction in people with spinal cord injury	90 (m) (40 with SCI, 50 without SCI)	Descriptive questionnaire*	Sexual response Sexual satisfaction
Li & Yau (2006)	Sexual issues and concerns: Tales of Chinese women with spinal cord impairments	10 (f)	In-depth interviews	Sexual activity Sexuality & rehabilitation
Parker and Yau (2012)	Sexuality and women with spinal cord injury	4 (f)	Semi-structured interviews	Sexual adjustment Sexuality & rehabilitation
Phelps et al (2001)	Spinal cord injury and sexuality in married or partnered men: Activities, function, needs, and predictors of	50 (m)	Multiple choice questionnaire *	Sexual response Sexual satisfaction Sexual adjustment Sexuality & rehabilitation

	sexual adjustment			
Potgieter and Khan (2005)	Sexual self-esteem and body image of South African spinal cord injured adolescents	4 (m) 3 (f)	Descriptive questionnaires * In-depth interviews	Sexual adjustment
Reitz et al (2004)	Impact of spinal cord injury on sexual health and quality of life	47 (m) 16 (f)	Descriptive questionnaire *	Sexual activity Sexual satisfaction Sexual adjustment
Richards et al (1997)	Women with complete spinal cord injury: A phenomenological study of sexuality and relationship experiences	15 (f)	Semi-structured interviews	Sexual response Sexual activity Sexual adjustment Sexuality & rehabilitation
Singh and Sharma (2005)	Sexuality and women with spinal cord injury	40 (f)	Interview questionnaire*	Sexual response Sexuality & rehabilitation
Tepper et al (2001)	Women with complete spinal cord injury: A phenomenological study of sexual experiences	15 (f)	Semi-structured interviews	Sexual response Sexual activity Sexual adjustment Sexuality & rehabilitation
Westgren and Levi (1999)	Sexuality after injury: Interviews with women after traumatic spinal	8 (f)	Structured interviews	Sexual activity Sexual concerns Sexuality & rehabilitation

Westgren et al (1997)	cord injury Sexuality in women with traumatic spinal cord injury	62 (f)	Structured interviews Descriptive questionnaire* Descriptive questionnaire *	Sexual activity Sexual satisfaction
White et al (1993)	Sexual activities, concerns and interests of women with spinal cord injury living in the community	40 (f)	Functional Independence Measure (FIM)	Sexual activity Sexuality & rehabilitation
TBI Articles				
Dombrowski et al (2000)	Rehabilitation treatment of sexuality issues due to acquired brain injury	2 (m) 1 (f)	Case studies	Sexual activity Sexual behaviour Sexuality & rehabilitation
Gaudet et al (2001)	Self-reported consequences of traumatic brain injury: A study of contrasting TBI and Non-TBI participants	26 (m TBI) 24 (f TBI), 22 (m non-TBI) 33 (f non-TBI)	Descriptive questionnaires *	Sexual satisfaction Sexual adjustment
Kreuter et al (1998)	Sexual adjustment and its predictors after traumatic brain injury	65 (m) 27 (f)	Descriptive questionnaire*	Sexual response Sexual activity Sexual satisfaction
O'Carroll et al	Psychosexual and	30 (m) 6 (f)	Golombok Rust	Sexual response

(1991)	psychosocial sequelae of closed head injury		Inventory of Sexual Satisfaction (GRISS) General Health Questionnaire Hospital Anxiety and Depression Scale (HAD)	Sexual activity Sexual satisfaction
Ponsford (2003)	Sexual changes associated with traumatic brain injury	143 (m) 65 (f)	Descriptive questionnaire *	Sexual response Sexual activity Sexual adjustment Sexuality & rehabilitation
Sandel et al (1996)	Sexual functioning following traumatic brain injury	39 (m) 13 (f)	Derogatis Interview for Sexual Function (DISF) Neuropsychological measures	Sexual response Sexual activity Sexual adjustment
Burn Articles				
Dobkin de Rios et al (1997)	Sexual dysfunction and the patient with burns	4 (m) 1 (f)	Case Reports	Sexual response
Bianchi (1997)	Aspects of sexuality after bur injury: Outcomes in men	40 (m)	The Sexuality Scale	Sexual adjustment
Connell et al (2012)	Sexuality following burn injuries: A preliminary study	268 (m) 94 (f)	Burns Specific Health Scale – Brief Version	Sexual adjustment Sexuality & rehabilitation

Meyer et al (2011)	Sexual attitudes and behaviour of young adults who were burned as children	50 (m) 42(f)	What Young People Believe and Do Questionnaire	Sexual activity Sexual adjustment
Parrott & Esmail (2010)	Burn survivors' perceptions regarding relevant sexual education strategies	Phase 1: 3(m) 5 (f) Phase 2: 3 (m) 1 (f)	Semi-structures interviews Focus group	Sexual adjustment Sexuality & rehabilitation
Robert et al (1998)	Impact of disfiguring burn scars on adolescent sexual development	10 (m) 9 (f)	What Young People Believe and Do – Revised (WYPBD)	Sexual activity Sexual adjustment

* Denotes questionnaires developed by the author for the purposes of their study and thus not validated. (m) = males (f) = females. Gender labels male and female were used as this is how gender was represented within the literature.

3.5.1 Physiological Effects of Trauma on Sexuality Post Trauma Injury

Physiological issues affected sexuality across all three trauma groups with sexual function, pain, medication side effects and decreased desire/libido being the most common factors. Gender comparisons have not been made due to the lack of gender specific sexuality research.

Decreases in sexual arousal and desire were common factors across most of the trauma groups reviewed.^{4, 5, 7, 8, 17-24} Whilst high rates of difficulties in sexual arousal correlated with decreases in sexual satisfaction, most studies did not include definitions of sexual arousal or sexual desire, and as such, it is difficult to ascertain which components of these processes have the greatest potential impact.

Understanding concepts of sexual desire and the processes of sexual arousal in both males and females are important, not only to understand the physiological changes that may occur post trauma injury, but to also understand the impact of treatment and rehabilitation methods and identify future research directions.

Psychotropic medications commonly used in the treatment of PTSD and depression following trauma injuries, have been noted to have secondary sexual dysfunction side effects.²⁵ Antidepressant medications, particularly selective serotonin reuptake inhibitors (SSRI's), have clinical implications that include pharmacological sexual dysfunction.²⁶ There were no conclusive studies relating to PTSD and sexual function in the three trauma groups selected, that included pharmacological prescription. Improvements in PTSD symptomology (e.g. depression) following sexual therapy have been noted in burn survivor rehabilitation, with these improvements occurring regardless of the implementation of psycho-pharmacological intervention, suggesting that pharmacological interventions played only a small part in the triggering of sexual dysfunction in this population.²⁵

Difficulties relating to sexual function including erectile or ejaculatory function, lubrication^{4, 5, 17, 24, 27, 28} and orgasm difficulties^{5, 6, 21-24, 28} were widespread within the trauma literature, particularly for SCI's. SCI literature identified that chronic pain and spasticity have been linked to increases in depression symptomology, decreased sexual arousal, and impaired erectile ability resulting in pain being associated with a negative impact on sexual function.²⁴ Pain was noted as a common reason for why SCI survivors avoided engaging in sexual activity.^{23, 27}

Bladder and bowel incontinence during sexual activity were amongst the most significant areas of concern for people with SCI and the associated embarrassment of this issue lead to sexual and relationship avoidance in this trauma group.^{12, 17, 22, 27, 29-}

³¹ Whilst there are many strategies for dealing with bladder and bowel management for sexual activity to reduce embarrassment for individuals, research suggests that addressing issues such as these are significantly influenced by the personal comfort levels of individual health professionals.³ Whilst medical and allied health staff may be comfortable dealing with genitalia in relation to personal care issues such as continence management, comfort levels decrease when the personal care issue is based upon sexual pleasure, leaving sexuality largely ignored.^{3, 16, 31, 32}

3.5.2 Cognitive-Genital Dissociation (CGD)

The process of “shutting down” or “shutting out” of sexuality based on the internalised perception that following trauma injury individuals are no longer capable of giving or receiving sexual pleasure,^{16, 33} was intrinsically linked within the literature with the exclusion of accurate, informative and timely sexuality related information and interventions within the rehabilitation setting,^{7, 12, 16, 33, 34} from sexuality specific trained staff.³⁵ Internalising inaccurate self-beliefs that a mutually satisfying and pleasurable sexual relationship post injury is not possible, lead to greater rates of depressive symptomology and decreases in overall QOL within the trauma literature.^{4, 21, 27, 36}

Potgieter and Khan³⁷ describe a dissociative process where individuals view their altered physical body as a dual entity following SCI. This process is characterised by individuals experiencing positive feelings towards their individual body parts whilst suppressing or dissociating their feelings towards their altered or impaired body. The result of this process is the perception of the altered body as an ‘enemy’. This is reinforced through the clinical handling of one’s body for the purpose of ADL’s by others, viewing one’s altered body as a source of problems/troubles and difficulty maintaining a wholistic body image which includes pleasurable touch, when sensation is absent in a significant portion of the body.

Decreases in sexual esteem and satisfaction were found to have strong correlations with greater rates of depression, anxiety and PTSD symptomology among the entire trauma groups reviewed.^{6, 16, 33, 34, 37} The exclusion of accurate sexuality information

and resources from rehabilitation services contributed to sexual difficulties, which had a direct impact on poor sexual esteem, sexual satisfaction and body image.^{6, 16, 31, 33, 38, 39} Individuals' internalised assumptions following major trauma that they are no longer desirable or capable as a sexual partner, were a significant factor in high rates of sexual avoidance behaviour amongst most trauma group survivors reviewed. The importance of including sexuality within rehabilitation programmes was reiterated throughout the literature for all trauma groups, as well as, an overall dissatisfaction with how sexuality is currently addressed. In general, research indicated that trauma survivors receive little or no advice from health professionals regarding potential direct and indirect changes to their sexuality as a result of their injury across the board.^{8, 16, 27, 33} This results in little or no avenues for trauma survivors to address sexuality issues, such as normalising insecurities and alleviating fears regarding changes to one's sexuality.

There was anecdotal evidence that standard sex therapy techniques, such as sensate focus, can facilitate significant improvements in QoL and intimate partner relationships in burn survivors.²⁵ They defined four potential factors that may contribute to sexual dysfunction following a burn injury; psychopathology factors (the presence of adjustment problems including PTSD and depression symptomologies), psychodynamic factors (changes in body image and self-esteem affecting arousal), medication side effects (sexual side effects of antidepressants on sexual function and desire) surgical and pain factors (the functional effects of contractures and tissue damage as well the effects of chronic pain on arousal). Unfortunately little or no empirical evidence to recommend the styles of therapy, timing of intervention, who is best to provide this intervention and how it should be initiated with patient's has been conducted extensively within any of the trauma group literature reviewed. However, there is acknowledgement within some of the literature for including health professionals specialising in sexuality in rehabilitation programs, due the complexities involved in sexual therapy and rehabilitation.^{20, 31}

3.5.3 Sexual Disenfranchisement (SD)

Decreased body image was a common phenomenon throughout the trauma research articles. Body image issues were generally seen as a complex issue, with a possible

stronger impact on female QoL outcomes, due to the perceived greater importance of internalised stereotypes of concepts of beauty on female self-esteem^{7, 12, 18, 27}.

The disconnection and disappointment associated with sexual disenfranchisement (SD) may result in individuals avoiding engagement in sexual activity with their partners due to the internalised belief or experience that sex is less satisfying post injury.³³ This may contribute to a loss of sexual self-esteem and confidence in the ability to experience sexual pleasure in an enjoyable way following trauma¹⁶. This may result from the exclusion of sexuality from rehabilitation services, lack of sexual counselling, asexual societal attitudes regarding people with disabilities, body image concerns and negative feedback regarding sexuality from health professionals and partners.^{16, 33} In general there were no correlations between the type of injury or injury severity with decreases in sexual satisfaction, sexual self-esteem or frequency of sexual activity; suggesting that trauma injury can have a major impact on an individual's sexuality, body image and interpersonal relationships, regardless of the nature of the trauma or length of time post trauma.

The negative impact of societal stereotypes on sexual self-esteem was evident across the three trauma groups reviewed. Internalising stereotypical scripts that people with disabilities are asexual, undesirable¹⁶ and the perceived taboo of an 'able' bodied person having a sexual relationship with a 'disabled' person, can have a negative impact on body image, sexual arousal^{17, 35} and depression symptomology.³⁵

Body-image dysphoria (BID) studies in non-trauma populations emphasize a multi-dimensional concept of body image which includes perceptual (accuracy of appearance related evaluations), subjective (levels of dissatisfaction, anxiety, or distress in relation to one's appearance) and social-behavioural (discomfort and avoidance of activities or situations that may bring attention to an individual's appearance issues) facets.⁴⁰ Connections between negative body image perception and psychosocial maladjustment were found within the trauma literature.^{17, 27, 37, 41, 42}

Scarring, disfigurement, deformity and loss of function, that are characteristics of many trauma injuries was found to lead to perceptual, subjective and social body image changes, resulting in decreases in body image satisfaction, behavioural and social avoidance.^{9, 16, 33} Evidence also suggests that this process is greater in females, who potentially place greater importance of normative social scripts of beauty based on media influences, on the subjective evaluations of oneself.³⁷

Research regarding severity of trauma and functional limitations on an individual's sexuality and relationship development are limited and contradictory. Several studies across the trauma groups indicate against popular thought that there is no significant correlation between injury severity as a predictor of psychosocial and sexual adjustment.^{1, 2, 19, 41, 43-45} For example, injury severity in terms of level of injury and completeness of spinal lesion have not been found to correlate to decreases in sexual satisfaction,⁵ sexual adjustment and quality of relationships post SCI,⁴¹ thus decreases in these areas have been found regardless of injury severity. However evidence within burn literature has found there is a correlation between impact of injury severity as measured by the percentage of total body surface area (TBSA) burnt and decreased sexuality and body image satisfaction have found in both males and females.⁹

3.5.4 Sexual Rediscovery (SR)

Sexual rediscovery has been characterised by an increase in sexual self-esteem,¹⁶ where there is an improved confidence in the ability to communicate one's own sexual needs with a partner.³³ Sexual experimentation was synonymous with renewed sexual interest and exploration. A willingness for both partners to explore a varied sexual repertoire and the corresponding perception that one's partner enjoyed the sexual component of the relationship were found to be important correlates of positive sexual experiences and satisfaction in trauma survivors.⁴¹ Exploring and developing a varied sexual repertoire as an integral component of sexual rediscovery and satisfaction was echoed throughout SCI and sexuality research.^{12, 17, 21, 27, 32} Common examples found within the literature of variations to sexual activity were exploration and stimulation of erogenous zones throughout the body,^{17, 27, 41} incorporating sexual aids/toys,^{12, 27, 41} incorporating fantasy,^{12, 22, 27} using the senses,²⁷ and incorporating erotic or pornographic media.¹² In addition spending time with one's partner participating in non genitally focussed intimacy, for example holding hands, and hugging and kissing were important factors in relationship and sexual satisfaction overall.^{27, 32, 45}

3.6 Chapter Discussion

Broadening the definitions of sexuality within the rehabilitation settings away from genitally focussed orgasm orientated influences, to incorporate intimacy, pleasure and variability sexual expression, would assist sexual adjustment.^{31, 32, 41}

Timing of addressing issues of a sexual nature is a crucial consideration within rehabilitation treatment planning.²⁷ Trauma survivors may initially experience CGD, whereby sexual exploration does not necessitate functional ADL tasks essential for discharge from hospital and reintegration to the home and workforce.¹⁶ As such the initial phases of rehabilitation may be too early to comprehensively address issues of changes in sexuality, therefore it is essential that sexuality services be available on an ongoing basis as part of outpatient services.^{27, 31} Post discharge, individuals may develop a greater understanding of their physical and sexual changes once discharged, that can be addressed more realistically within outpatient sexual counselling and rehabilitation services,³¹ provided the patient can still access these services overtime.

Sexual medicine and rehabilitation is concerned with sexuality changes, dysfunction or problems in people who have a congenital or acquired physical impairment due to disease, injury or secondary to medical interventions.⁴⁶ Hatzichristou, Rosen, Derogatis, Low, Meuleman, Sadovsky's⁴⁷ article outlining recommendations for the clinical evaluation of men and women with sexual dysfunctions, from the "Clinical Evaluation and Scales in Sexual Medicine" committee of the International Consultation in Sexual Medicine (ICSM), identify three basic principles for the management of sexual problems in the clinical setting. These principles are: 1) the adoption of a patient-centred framework, with emphasis on cultural competence in medical practice (taking into account biopsychosocial factors in accordance with the World Health Organizations definitions of health;¹³ 2) Application of evidence based medicine in diagnostic and treatment planning (assessment and treatment should be guided by best evidence based research and practice) and 3) Use of a unified management approach in evaluating and treating sexual problems in both men and women (this is described as incorporating the need for gender equality in sexual medicine, although the authors of this review suggest this should include further expansion of concepts of gender and diverse sexual orientations). Whilst these guidelines have been described in terms of sexual medicine, it provides a potential

framework for working with sexuality changes that can be adapted to the multidisciplinary healthcare setting.

Hatzichristou, Rosen, Derogatis, Low, Meuleman, Sadovsky⁴⁷ classify sexual dysfunctions a i) psychogenic (the absence of biological findings; ii) organic (Biological findings, although not significant mental/cognitive or emotional/affect distress and iii) Mixed (biological findings with significant mental/cognitive or emotional/affect distress. The authors stress that organic and psychogenic factors are often both present, particularly for those with long-standing sexual function problems. An alternative classification of sexual dysfunction following trauma or chronic illness, that is potentially better suited for a multidisciplinary clinical context, is that described by Foley and Gimbel.⁴⁸ They describe three levels of sexual changes for people with multiple sclerosis; primary, secondary and tertiary; although it is our belief that these levels of sexual changes could apply to all trauma and chronic illness groups. Primary sexual changes relate to nervous system damage that impairs physiological aspects of sexual response, for example decreases in sexual desire, painful or unpleasant genital sensations, and changes to frequency and/or intensity of orgasmic response. Secondary changes relate to other symptoms and/or physical limitations that indirectly impact sexual response for example difficulties with bowel and bladder continence during sexual activity, fatigue, and muscle weakness limiting body positioning. Lastly, tertiary sexuality changes result from psychosocial and cultural issues that can have a negative impact on sexual esteem, body image and sexual satisfaction for example changes in roles, lifestyle and participation in social, work or leisure activities. Tertiary sexual changes may also be linked with greater rates of depression, decreased self-esteem and decreased body image for people with disabilities.^{16, 49, 50}

Whilst any classification system of health related issues should be utilised with caution and/or care, they do provide a potential framework in which the combination of biopsychosocial issues can be factored into screening within the clinical setting for assessment and treatment planning. There were no individual or multicentre clinical trials of screening or assessment tools of sexuality changes for use by health professionals in any of the trauma group literature included in this review. This finding highlights a significant gap in evidence based knowledge and practice for all trauma diagnostic groups that requires further attention with empirical research.

Of the 36 eligible articles included in this review, only three included a validated sexuality related outcome measure. The three measures that were included within the literature reviewed were all designed primarily for research use and are, therefore, potentially not suited for the multidisciplinary clinical setting. In addition, there have also been some construct validity issues identified with 'The Sexuality Scale'.⁵¹

The Female Sexual Function Index (FSFI) developed by Rosen, Brown, Heiman, Leiblum, Meston, Shabsigh⁵² was designed as a brief, valid and reliable self-reported measure for use as clinical trials assessment instrument. The authors state that the FSFI addresses the multidimensional nature of female sexual function based on five factors/domains; a) desire and subjective arousal, b) lubrication, c) orgasm, d) satisfaction and e) pain and/or discomfort.⁵² The FSFI is a 19 item self-administered questionnaire that has been validated for use in clinical trials or epidemiological studies of sexual function in women.⁵² There are sexual function inventories for men that have been published and used within research regarding male sexual function the International Index of Erectile Function (IIEF)⁵³ and The Brief Male Sexual Function Inventory (BMSFI).⁵⁴ Although these tools have been designed primarily for identifying issues relating to erectile dysfunction more so than psychosocial determinants of sexual changes, they may have relevance in the research setting as part of a variety of assessment tools investigating sexuality changes post trauma injury.

The Derogatis Sexual Functioning Inventory (DSFI) is another human sexual function inventory for use with both males and females that has been widely used in sexuality research.⁵⁵ This is a 254 item questionnaire arranged into 10 sub-tests; information, experience, drive, attitudes, psychological symptoms, affects, gender role definition, fantasy, body image and sexual satisfaction.⁵⁵ The authors state that it can be self-administered by participants regardless of marital status or sexual orientation.⁵⁵ It was designed to be utilized as an outcome measure and this combined with the administration of this tool being approximately 60 minutes or longer, limits its use in the clinical setting. However, as a validated multidimensional tool it does have the potential to be used in individual or multicentre research into sexuality changes for trauma survivors.

Hatzichristou, Rosen, Derogatis, Low, Meuleman, Sadovsky⁴⁷ endorse the use of the Brief Sexual Symptom Checklist (BSSC) for Men and the BSSC for Women as well

as the Sexual Complaints Screener (SCS) for Men and SCS for Women as screening tools for the clinical setting developed by the ICSM.⁴⁷ This endorsement is given in the context of sexual medicine, therefore further research is required to assess if these screening tools are appropriate for the multidisciplinary rehabilitation setting to identify sexuality changes for trauma survivors.

Lastly the PROMIS[®] Sexual Function and Satisfaction Measures Brief Profile (PROMIS[®] SexFS) is a customizable research tool that can be self-administered by participants of diverse gender and sexual orientation.⁵⁶ Whilst its validity is for use in cancer populations, the measure is intended for use across a broad range of diagnostic groups. The PROMIS[®] SexFS includes 81 items in 11 domains; Interest in Sexual Activity, Lubrication, Vaginal Discomfort, Erectile Function, Global Satisfaction with Sex Life, Orgasm, Anal Discomfort, Therapeutic Aids, Sexual Activities, Interfering Factors and Screener Questions.⁵⁶ This is a relatively new tool that is currently being tested in other target groups other than cancer, thus may be a tool that has some future validity in the trauma population.

Whilst more comprehensive sexual rehabilitation should be advocated on an outpatient basis, providing a culture within acute rehabilitation services where the acknowledgement of sexual issues is initiated by staff, is essential to foster positive experiences of sexuality rehabilitation, and to decrease potential fear of trauma survivors when asking questions about their sexuality in the future.^{27, 31}

3.6.1 Limitations of the Study

Due to the lack of research articles for burn and TBI trauma, results must be viewed with caution. For example, there was no evidence from the literature in relation to burns survivors having difficulties with libido/sexual arousal, however with only a limited number of research articles sourced that focused solely on aspects of sexuality; it is possible that this issue has not been researched adequately within this trauma cohort.

3.7 Chapter Conclusions

Trauma injury can have a significant impact on an individual's sexuality resulting in difficulties in psychosocial adjustment. Although this is an important issue, sexuality has been largely ignored within trauma research and rehabilitation. There is an urgent need for quality empirical research across all trauma groups, to develop effective comprehensive therapeutic rehabilitation strategies relating to sexuality, in order to facilitate improvements in the quality of life of all trauma survivors.

Collaborative research with medical, allied health and sexuality based researchers is required to ensure that research includes; sexual diversity, broader perspectives of sexuality and acknowledges the differences in sexual response between males and females.

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Chapter 4: A Literature Review to Determine the Impact of Sexuality and Body Image Changes following Burn Injuries.

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4.1 Chapter Introduction

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The inference from the previous strand of study presented in chapter three was that trauma injury has a significant impact on sexuality and body image, which is not adequately addressed in healthcare services.

The aim of this strand of study was to investigate the literature to investigate the issues surrounding adjustment to sexuality and body image changes, post-burn injury.

4.2 Abstract

Objective: The purpose of this study was to perform a review of the existing literature to a) determine the impact of sexuality and body image changes following burn injuries in an adult population and b) identify if there is a relationship between the two variables and the impact this potentially has on burns survivors' quality of life (QoL).

Method: A total of 16 research articles; sexuality (n=5) and body image (n=8), sourced from online databases were reviewed. Both quantitative and qualitative studies that investigated adult burn survivors in both inpatient and outpatient settings were included in this review.

Results: The literature suggests there is an interaction between body image dissatisfaction, sexual satisfaction and long-term psychological adjustment, particularly for female burn survivors. However, methodological limitations of the studies reviewed limits the transferability of the findings to clinical practice. Three themes were identified throughout the literature; satisfaction/dissatisfaction, adjustment issues and stigmatisation.

Conclusions: Changes in body image and sexuality have a potential negative effect on burn survivors' long-term quality of life. Further collaborative empirical research is required to understand the incidence and prevalence of these issues as well as intervention studies evaluating treatment programs for best practice.

4.3 Introduction

Body image, often referred to as body esteem, has been described as the internalised cognitive perceptions that an individual has of his/her body in terms of attractiveness, social attractiveness and the feel of how one's body performs functionally.^{1, 2}

The link between sexuality and body image in a normative population is under researched; however, Pujols, Meston and Seal³ attempted to do so in their study that investigated multiple body image variables to understand the relationship between body image and sexual satisfaction domains in females. Their community cohort internet based study of females (N=154) found higher levels of body image esteem to be correlated with greater sexual satisfaction. Items from the Sexual Attractiveness Scale, administered as part of this study, were also found to have a strong relationship with sexual satisfaction. The authors state that their study is the first to show the relationship between body image and sexual satisfaction after controlling for sexual function. This relationship suggests that it is important to include body image as an important component of sexuality when clinically addressing sexuality in a 'normal' population. How this relationship affects females with disfiguring injuries such as burns has not been investigated, thus the impact and treatment implications are currently unknown.

The aims of this literature review were to, a) determine the impact of sexuality and body image changes following burn injuries in an adult population and b) identify if there is a relationship between the two variables and the impact this potentially has on burns survivors' quality of life (QoL). To address these aims this review was guided by the following questions: 1) what are the experiences of adult burn survivors regarding how changes in their sexuality and body image impact their QoL? and 2) does the literature demonstrate evidence that there is a relationship between negative sexuality and body image changes and greater body image dissatisfaction, sexual dissatisfaction and QoL?

4.4 Chapter Methodology

4.4.1 Search Strategy

A search of the literature for published peer reviewed journal articles was performed using the following online databases; Proquest, OVID, Medline, Cochrane Library, Springer link and Science Direct. Burn* and burn injuries were used as free text with sex*, sexual*, sexual adjustment, sexual satisfaction, body image*, body image distress, body image dissatisfaction, body esteem as key words.

A total of 35 articles regarding sexuality and/or body image were sourced; sexuality (n=9) and body image (n=26). After further reading of abstracts 19 articles were excluded (sexuality (n=4) and body image (n=18) as they did not meet the inclusion criteria. A total of 16 articles meet the inclusion criteria, sexuality (n=5) and body image (n=8).

4.4.2 Inclusion Criteria

Both quantitative (QUAN) and qualitative (QUAL) studies that investigated adult (16 years old and above) burn survivors in both inpatient and outpatient settings were included in this review. QUAN studies were included if they evaluated sexuality and body image changes in adult burn survivors through intervention outcome measures and/or QoL scales in the form of validated surveys and questionnaires. QUAL studies were included if they investigated the 'lived' experience of sexuality and body image changes in burn survivors and their impression of how these changes had affected their QoL (Table 4.1).

4.4.3 Exclusion Criteria

Articles that did not primarily address body image, literature reviews, opinion pieces and articles that included data from individuals less than 16 years of age were all excluded (Table 4.1).

4.5 Chapter Results

Five of the eight body image articles included in this study used the Satisfaction with Appearance Scale (SWAP) as a measure of body image dissatisfaction (BID). Other measures used included: Burns Specific Health Scale – Brief (BSHS-B), Beck Depression Inventory (BDI), Short Form SF-36 and SF 12 Health Survey, The COPE, Importance of Appearance Scale of the Multi-dimensional Body-Self Relations Questionnaire (MBSRQ-IA), World Health Organization Disability Assessment Schedule II (WHODAS II), Body esteem Scale for Adolescents and Adults

4.5.1 Satisfaction / Dissatisfaction

Five studies have investigated the impact of body image dissatisfaction (BID) in burn survivors,⁴⁻⁸ however, there have been only two studies investigating satisfaction/dissatisfaction regarding sexuality post-burn^{9, 10} and only one of these investigates both body image and sexuality satisfaction/dissatisfaction over time.¹⁰ The Satisfaction with Appearance Scale (SWAP) and SF-36 were used as a measure in four of the five studies that investigated BID in burn survivors.^{4, 6-8} The SF-12 was used in Chondronikola, Sidossis, Richardson, Temple, van den Berg, Herndon's⁵ study as opposed to the SF-36. All five studies, however, used different questionnaires and scales to measure the impact of BID on perceived depressive symptomologies, stigmatisation and importance of appearance.

Conclusions regarding sexual satisfaction/dissatisfaction in the burns population were limited, not only in terms of the small number of articles dedicated to this area, but also in methodology. Two of the five articles used qualitative research methods; one used a phenomenology based research design in which the research consisted of a combination of semi-structured interviews and one focus group¹¹ and the other outlined five case reports of varying types of sexual dysfunction that may be found with burn survivors¹². The three quantitative research method articles^{9, 10, 13} all used different questionnaires and scales to measure sexual satisfaction, thus there is no consistency or generalizability with the findings. In addition, the majority of the sexuality related studies were based on very small sample sizes, especially for females (Table 4.1).

Table 4.1: Adult Studies of Body Image and Sexuality Changes Post-burn Injury

Author(s)/date	Title	Sample	Measures
Body Image Articles			
Bergamasco et al (2002)	Body image of patients with burns sequelae: evaluation through the critical incident technique	N= 35 (males n=23, females n=12)	<ul style="list-style-type: none"> • BDI • SWAP • SF:36
Chondronika et al (2013)	Impact of obesity in body image dissatisfaction and social integration difficulty in adolescent and young adult burn injury survivors	N= 68 (Males n- 46, females n=22)	<ul style="list-style-type: none"> • BSHS-B • SF-12 • WHODAS II • Weight measures (including BMI)
Fauerbach et al (2000)	Effect of early body image dissatisfaction on subsequent psychological and physical adjustment after disfiguring injury	N=86 (males n= 67, females n= 19)	<ul style="list-style-type: none"> • SWAP • Davidson Trauma Scale • BDI • SF:36
Fauerbach et al. (2002)	Coping with body image changes following a disfiguring burn injury	N=78 (males n=59, females n=18)	<ul style="list-style-type: none"> • COPE • SWAP
Lawrence et al (2004)	Visible vs. hidden scars and their relationship to body esteem	N= 361 (females 52%)	<ul style="list-style-type: none"> • Demographic Questionnaire* • Burn Characteristics Questionnaire* • Perceived Stigmatization Questionnaire* • Social Comfort Questionnaire* • ISEL – 12 • BES • Importance of Appearance Scale • The Short Mood and Feelings Questionnaire Adult Version • Worry About Appearance*

Moi et al (2008)	The experience of life after burn injury: a new bodily awareness	N=14 (males n=11, females n=3)	<ul style="list-style-type: none"> Open in-depth interviews
Thombs et al (2007)	Depression in burn reconstruction patients: symptom prevalence and association with body image dissatisfaction and physical function	N = 224 (males n=122, females n=102)	<ul style="list-style-type: none"> BDI SWAP SF:36
Thombs et al (2008)	From survival to socialization: a longitudinal study of body image in survivors of severe burn injury	N= 79 (males n= 55, females n=24)	<ul style="list-style-type: none"> SWAP Importance of Appearance sub-scale (from MBSRQ-IA) SF:36
Sexuality articles			
Dobkin de Rios et al (1997)	Sexual dysfunction and the patient with burns	N=5 (males n=4, females n=1)	<ul style="list-style-type: none"> Case Reports
Meyer et al (2011)	Sexual attitudes and behaviour of young adults who were burned as children	N=92 (males n=50, females n= 42)	<ul style="list-style-type: none"> What Young People Believe and Do Questionnaire
Parrott & Esmail (2010)	Burn survivors' perceptions regarding relevant sexual education strategies	Phase 1 N= 8 (males n=3, females n=5) Phase 2 N= 4 (males n=3, females n=1)	<ul style="list-style-type: none"> Semi-structures interviews Focus group
Tudahl et al (1987)	Sexual satisfaction in burns patients	N=54 (males n=44, females n=10)	<ul style="list-style-type: none"> Whole Quality of Life Study (Sexual function portion)
Body Image and Sexuality Combined			
Connell et al (2012)	Sexuality following burn injuries: a preliminary study	N= 362 (males n=268, females n=94)	<ul style="list-style-type: none"> BSHS-B

* Questionnaires developed by the author(s) and thus not validated.

Four articles found that females reported greater psychological distress, shame and depressive symptoms as a result of their burn injuries.^{4, 8, 10, 14} These articles suggest that females are more susceptible to developing BID and the associated negative psychological impacts of BID, due to the greater expectations of the importance of attractiveness in society for females.^{8, 14} Similarly decreased sexual satisfaction has also been found to impact females to a greater extent than males.⁹ Tudahl, Blades and Munster⁹ found that females had a significantly higher correlation between

physical function and sexual satisfaction and between body image and sexual satisfaction, compared to males. Whilst there were many limitations in this study, including small sample size (especially for females n=10) and data being collected at one time point with the average time post-burn being 30.8 weeks, this study did highlight that more research is required regarding the issues of sexuality following burns. Connell et al's¹⁰ analysis of the Burns Specific Health Scale – Brief (BSHS-B), found that 18.4% of burn the burn survivors surveyed felt frustrated because they were not able to be sexually aroused as well as they used to (item 21 of the BSHS-B) and 21.8% of participants reported that they were not interested in sex anymore, at 12 months post injury. Findings suggested that rather than improving in line with physical function improvements, the sexuality domain of the BSHS-B decreased over time. This study did find that whilst both males and females reported similar frequency rates of impact in the sexuality domain of the BSHS-B, the severity of this impact was significantly higher for females. Likewise, Fauerbach, Heinberg, Lawrence, Munster, Palombo, Richter⁷ found that when adjusting for the effects of distress, improvements in physical function were not related to BID in burn survivors.

Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach's⁴ longitudinal study of body image in survivors of severe burn injuries found that those with smaller total body surface area (TBSA) of burn improved substantially over a twelve month period, whereas those with a larger TBSA reported greater dissatisfaction with their body image over this time. This was found for both males and females, however, was more pronounced in the female participants. A second major finding of this study was that there was a significant relationship between pre-burn psychosocial functioning and post-burn psychosocial functioning, and that this relationship was mediated by body image satisfaction/dissatisfaction. This suggests that dealing with changes in appearance is an important component of adjustment following a severe burn injury. Fauerbach, Heinberg, Lawrence, Munster, Palombo, Richter⁷ supports this finding. They found that there was a relationship between BID and difficulties with the mental and physical domains of the SF: 36 over time, after controlling for injury severity. Like Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach,⁴ this study concludes that early BID is a potentially clinically unique indicator of future psychological health related QoL.

Lawrence, Fauerbach, Heinberg and Doctor ⁶ study of the visibility of scarring in relation to body esteem found that scar visibility correlated to increased worry about appearance. In addition, there was a low, but significant, relationship between body esteem and participants self-appraisals of their appearance. Unlike Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach,⁴ burn severity was not correlated to depressive symptoms or increases in worry about appearance. However, an earlier study by Thombs, Haines, Bresnick, Magyar-Russell, Fauerbach and Spence ⁸ also suggested that larger burns and the visibility of the burn has more psychological impact on females, than males. This finding was linked to a disproportionate number of females seeking reconstructive surgery compared to males. Path model analysis showed that female gender, mediated by BID had a significant correlation to depressive symptoms, thus screening for depression should be included when evaluating patients seeking reconstructive surgery.

4.5.2 Adjustment

Whilst the majority of the articles relating to body image and sexuality following burns predominantly addressed issues of body image satisfaction/dissatisfaction, adjusting to changes in these domains was seen within the literature as an important component of the long term QoL for burn survivors.^{4, 6, 7, 14, 15} However, whilst adjustment was a significant theme identified within the literature, Fauerbach, Heinberg, Richter, Lawrence and Bryant ¹⁵ was the only article to report research on adjustment schema in the form of emotion-focused coping styles on distress symptoms and levels of BID. Fauerbach, Heinberg, Richter, Lawrence and Bryant ¹⁵ describe two types of emotion focussed coping mechanisms to deal with stressful life situations, such as burn injuries. In order to cope with the associated emotions following such a stressful event, patients may either adopt an avoidance approach (i.e. suppression of distressing thoughts or feelings) or a processing approach (i.e. actively process the thoughts and feelings associated with the distress). Fauerbach et al (p. 116)¹⁵ on the basis of Wegner's (1994) mental control model, suggests that motivation is the main driver of which emotion-focused coping strategy a person will engage in. Central to this motivation is the need for 'controllability' (the prevention of distress through the suppression of adverse thoughts, feelings or cues) and 'predictability' (the prevention of adverse surprise through an ongoing processing of

adverse stimuli, thoughts or feelings). It is proposed by the authors that in the case of BID in burn survivors, when individuals experience distressing thoughts, cognitive mechanisms are engaged as means to control the thought processes. The 'operating system' which is consciously controlled, mentally searches for thoughts that are consistent with the desired mental state. In doing so the operating system suppresses thoughts that are not consistent with the desired mental state. The 'automatic monitoring system', which is not consciously controlled, scans thoughts nearing the consciousness for those thoughts that are not consistent with the desired state and brings those thoughts to the consciousness so that they can be picked up by the operating system and suppressed as required. When cognitive capacity is limited due to secondary factors such as pain or distress, the monitoring system is still able to perform its scanning and thought feeding function, however, the operating system is less capable of performing its suppressive function. As a result of an impaired suppressive function, there is a rebound of unwanted thoughts. Fauerbach, Heinberg, Richter, Lawrence and Bryant¹⁵ claims that in the case of a burn survivor emotionally coping with the change in their appearance, where the controllability motive is foremost, the individual engages the operating system to control distress by suppressing aversive thoughts. When the predictability motive is foremost for an individual, they will use the operating system to scan for distressing thoughts in order to predict aversive stimuli and thus actively process and cope with the distressing thoughts. When there is limited cognitive capacity and the operating system is not able to perform its suppressing task, a 'rebound' effect occurs whereby the opposing motive and its associated coping strategy is interchanged.¹⁵ Fauerbach, Heinberg, Richter, Lawrence and Bryant's¹⁵ study hypothesized that the use of two emotion-focused coping strategies combined (i.e. mental disengagement and venting) would correlate to greater levels of BID than those that used neither strategy or just one of these coping strategies alone. The participants who predominantly used a combination of both emotion-focused coping strategies (suppression and venting), demonstrated significantly higher levels of BID, compared to the groups that used either one or neither of the emotion-focused coping strategies. The combination of both emotion-focused coping strategies, thus resulting in insufficient suppressive processing of aversive stimuli, may lead to increased perpetuation of an ambivalent or maladaptive coping style that results in the reoccurrence of depressive, intrusive or avoidant thoughts. The authors see this

as supporting evidence for Wegner's (1994 as cited in)¹⁵ mental control models in relation to adjustment and coping following disfiguring burn injuries.

Bergamasco, Rossi, Amancio and de Carvalho¹⁴ describe BID as being very personal in nature, with individual characteristics. This study found that there was a relationship between perceptions of BID and feelings of fear, which was reported in nineteen of the thirty-five participants. These feelings of fear were associated with difficulties in relationships, fear of work difficulties and fear of loss of upper and lower limb function. As an adjustment mechanism to cope with these fears, eighteen participants reported rebelling against their current situation as well as their treatment regime. Denial and avoidance behaviours were also noted as coping strategies utilised by participants. Avoidance behaviours in particular lead participants not only to hide their physical bodies with clothing, but to hide themselves socially, effectively resulting in loneliness and isolation.

No studies investigated adjustment and coping models or strategies to deal with sexuality changes following burns. Parrott and Esmail's¹¹ study of perceptions of relevant sexual education strategies for burn survivors found that adults who were burnt as children identified that they had similar thoughts and feelings towards their sexuality as their non-burnt peers. However, mainstream sexuality education did not fully address issues that are unique to burn survivor such as, knowing how to expect scarred skin to react for example on the abdomen during pregnancy, dealing with body image issues and acceptance of themselves and of other people's reactions. This study concluded that sexuality education programs specific to burn survivor's needs was warranted and should be supplementary to mainstream sexuality education. Integrating a burn specific sexuality education program into a burn camp environment or peer support group setting where age appropriate peer interactions could take place, were seen as the most appropriate locations for such a program.

4.5.3 Stigmatisation

The impact of unsolicited questions, comments and stares and the resulting feelings of stigmatisation felt by burn survivors was an issue that was prominent throughout the body image following burn injury literature.^{4, 6, 14, 16} There were no research articles that addressed these issues in relation to sexuality.

Bergamasco, Rossi, Amancio and de Carvalho's¹⁴ phenomenology based research involving semi-structured interviews found that twenty participants (n=35) reported negative and stigmatising interpersonal reactions from strangers in the community. These stigmatising reactions were generally identified as staring, curiosity, making comments and making jokes about the individual. There were no reports from participants of positive social consequences or reactions. Participants in this study also reported that the strangers staring at them surpassed curiosity, instead it was experienced as malicious and judgemental. Moi, Vindenes and Gjengedal¹⁶ using a Husserlian phenomenological method of using semi-structured interviews, also found that burn survivors experienced regular staring and pointing from strangers. Participants in this study identified that these experiences were unpleasant and resulted in feelings of stigmatisation and loss of anonymity. Whilst these reactions were obviously hurtful to the burn survivors, participants demonstrated some resilience to these situations in the form of understanding, humour, forgiveness of others own insecurities and to neglect the rudeness of the encountered reactions of strangers.

Unfortunately this stigmatisation contributes to difficulties with adjustment and coping with a burn injury and in turn can lead to psychosocial isolation.^{6, 14, 16} Lawrence, Fauerbach, Heinberg and Doctor⁶ found that there was a consistent relationship between burn severity and attributions of others in relation to body esteem measures. In addition the visibility of scarring was correlated with more startled, confused behaviour and greater perceived hostility. Connell et al's¹⁰ BSBS-B analysis of the body image and sexuality domains, found that the internalised perception of the attractiveness of the burn to others was had the highest frequency of negative response in both males and females, however, the severity of the negative response greater for females.

4.6 Chapter Discussion

There is evidence to suggest a causal effect of body image on sexual satisfaction and sexual esteem within 'normal' population studies.³ Using the Sexual Satisfaction Scale for Women (SSS-W), the Body Esteem Scale (BES) and the Female Sexual Function index (FSFI), Pujols, Meston and Seal³ performed a multiple regression analysis with sexual satisfaction as the dependent variable and variables of body

image as predictors to test the hypothesis that body image variables would predict sexual satisfaction (whilst controlling for sexual function). Results indicated that body esteem and appearance-based distracting thoughts that occurred during sexual activity, were significant predictors of sexual satisfaction. Consistent with their hypothesis results also indicated that all subscales of the BES were positively correlated with sexual satisfaction, thus higher levels of body esteem were associated with great levels of sexual satisfaction. The researchers suggest that their findings show evidence that cognitive appraisals of one's body during sexual activity, body weight and size, perceptions of attractiveness and physical conditioning and function, are potentially important components of women's' sexual satisfaction. As these findings suggest a strong interaction between body image perceptions and sexual satisfaction, the authors recommend that body image assessment should be a component of clinical practice and treatment planning, especially for women who may present with sexual problems such as low sexual satisfaction. The researchers acknowledge that there are limitations to their study, namely that it was a community internet based study whereby the generalizability of the findings are limited by the homogeneity of the sample with regard to education and ethnicity. In addition, there were no women over the age of 50 years old, therefore the effects of age related body image and sexuality changes are not factored into. However, this study is one of the first to investigate the interaction of body image and sexuality and thus is an important consideration for future sexuality and body image based research. This link has not been studied within the burn survivor population. However, the literature included in this review does suggest that there is a relationship between BID and sexual satisfaction and adjustment to changes in these health domains that warrants further investigation.

There is no longitudinal epidemiological evidence within the literature as to the incidence and prevalence of low body image and or social anxiety in burn survivors.¹⁷ There is some evidence to suggest that there are factors that may be risk factors that influence adjustment post-burn and in turn impact levels of BID and perceived stigmatisation, including low social support,¹⁷ the importance of appearance pre-burn injury⁶ and female gender.¹⁰ In addition there were no studies found during this review process that specifically investigated the perceived perceptions of appearance by others¹⁷ or perceived satisfaction of appearance/attractiveness of significant others. Whilst Connell et al's¹⁰ longitudinal

study of Burn Specific Health Scale-Brief body image and sexuality domain responses is only preliminary in nature and thus is limited in terms of its generalizability, it does suggest that psychosocial changes to body image and sexuality do not improve over time, especially for females and those with larger TBSA. Due to the potentially enduring nature of the psychological impact of body image issues and the lack of current epidemiological information, further research is warranted both in the burns community and in conjunction with of disfiguring conditions to highlight this issue as an important component of Public Health. Whilst many of the studies identified that body image esteem and sexual esteem programs should be included in burn rehabilitation,^{4, 6, 8, 11, 14} there were no intervention evaluation studies found for any treatment regimens to assist in the rehabilitation of body image or sexuality changes in the adult burn population. Blakeney, Thomas, Holzer, Rose, Berniger and Meyer¹⁸ evaluated an intensive short-term CBT based social skills program for adolescents, the hypothesis being that this treatment would have positive impact on lowering behavioural problems for those in the treatment group. Whilst the authors suggest that their findings confirmed their hypothesis, this study had significant methodological limitations and results did not support the suggestion that the treatment was more effective than the control. The treatment group did demonstrate fewer somatic complaints 1 year post treatment, however, both groups reported diminished anxiety, improvements in aggression and showed no significant changes in rule-breaking behaviour, therefore it cannot be discounted that these improvements were potentially spontaneous in the treatment group as they were in the control group. Whilst there is a lack of empirical evaluation of suggested treatment techniques, the literature does support the inclusion of cognitive behavioural therapy (CBT) for social anxiety and social skills training as useful therapeutic strategies in rehabilitation programs to improve self-esteem and social comfort in burn survivors.^{4, 6} Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach⁴ describes social skills training as incorporating strategies to teach burn survivors to effectively anticipate and manage the reactions of others. The desired result of these strategies is to encourage positive feedback, increased self-esteem and increased confidence. Lawrence, Fauerbach, Heinberg and Doctor⁶ also supports this recommendation, stating that interventions aimed at improving body esteem of burn survivors, should include strategies to improve social comfort. It is essential that further empirical research, which includes

the relationship between body image and sexuality and intervention evaluations, is conducted to provide best practice evidence for rehabilitation programs.

4.7 Chapter Conclusions

This review highlights the evidence that changes in body image and sexuality have a potential negative long term effect on burn survivors QoL. In addition BID is a unique mediator between pre-burn and post-burn psychosocial function. This relationship is independent of improvements in physical function. Whilst the importance of incorporating body image and sexual esteem strategies in burn rehabilitation, there have been no studies evaluating best practice in the provision of these strategies, timing of these programs and the most appropriate multidisciplinary approach to incorporate these programs in the adult burn population. Further research is therefore recommended to not only further investigate the prevalence, incidence and lived experience of body image and sexuality changes, but also in way that these issues can be screened and addressed over time within intervention programs to help facilitate greater improvements in QoL outcomes for burn survivors.

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Chapter 5: Sexuality Following Burn Injuries: A Preliminary Study

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5.1 Chapter Introduction

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The inference from the previous strand of study presented in chapter four was that burn injuries result in changes to sexuality and body image esteem, which are correlated with lower quality of life experiences for survivors.

The aim of this strand of study was to investigate preliminary data, from a Western Australian burn clinic cohort, to investigate the potential incidence and prevalence of sexuality and body image in burn survivors.

5.2 Abstract

Objectives: Responses to the sexuality and body image sub-domains of the Burn Specific Health Scale- Brief Version (BSHS-B) were analysed, to identify the incidence of sexuality and body image changes in burn survivors from hospital discharge – 12 months post injury.

Methods: Data was collected through examination of Burn specific Health Scale Brief Version questionnaires (BSHS-B), from burns patients at hospital discharge and one, three, six and twelve month time points post-burn injury.

Results: The results demonstrate that burn injuries have a significant negative impact on sexuality and body image satisfaction for burn survivors. The results raises concerns regarding potential long term quality of life (QoL) issues for burn survivors in these domains.

Conclusions: Sexuality and body image following burn injuries are important QoL domains that should be addressed during post injury rehabilitation. This preliminary study shows that further empirical research regarding changes to sexuality and body image in the burns population is required.

5.3 Introduction to the Study

Burn injuries are often sudden and traumatic injuries characterised by physical (function limitations and disfiguring scarring) and psychosocial (quality of life, self-esteem, social interaction and sexuality) long term effects.¹⁻³

Generally research has shown a strong correlation between poor body image and lower sexual satisfaction.⁴⁻⁶ Specifically there is limited published research regarding the relationship between body image and sexuality in burn survivors. However, it has been suggested that this relationship between poor body image and decreased sexual satisfaction in burn survivor populations is similar to that found in research conducted in non-burn populations.⁷

5.3.1 Sexuality and Quality of Life (QoL)

The relationship between the skin and its role in the biopsychosocial elements of sexuality and social interactions has had very little attention within burn research. The importance of touch in the emotional aspects of intimacy formation and sexual expression cannot be underestimated.⁸ Tactile sensation is an integral component during the processes of sexual response and the impact scar tissue has on these processes are potentially multiple. Hyposensitivity and hypersensitivity both within scar margins and globally, which is common in burn injuries, may result in secondary sexual dysfunctions, however, there are no studies investigating this issue in people with burn injuries.

There is empirical evidence for the health benefits associated with sexual activity such as; a reduction in depression rates, post-traumatic increased happiness, pain reduction, increases in life expectancy to name a few.⁹ With high rates of depression and Post Traumatic Stress Disorder (PTSD) in the burn survivor population, addressing sexuality should be an integral component of rehabilitation services.

5.3.2 Body Image

Sexuality and body image are important domains of concern within rehabilitation programs,^{10,11} however, research regarding the impact of sexuality and body image changes is limited. In addition results from studies that have been conducted particularly with regard to the association of size of burn as measured by total body

surface area (TBSA) and body image, changes have been inconsistent. Pope et al's.¹² study of young burn survivors found that there was a positive correlation between TBSA and greater dissatisfaction with appearance as measured by The Body Esteem Scale for Adolescents and Adults (BES). Thombs et al's¹³ longitudinal study of body image dissatisfaction (BID) in severe burn injury survivors also found an association between larger TBSA and increased BID over time, especially in females. In contrast other studies have not found such clear associations between TBSA and BID. Orr, Reznikoff and Smith's¹⁴ study of burn injured adolescents and young adults indicated that TBSA and location of scarring did not correlate with predictions of greater self-esteem and BID. Likewise Heinberg et al¹⁵ found that body image distress/BID did not correlate with indicators of TBSA when investigating psychological involvement in decision making to undergo reconstructive surgery following burns. Thombs et al.¹³ critiques the other studies by suggesting that they investigated body image measures at one time point, therefore they do not show potential impacts over time.

Body image dissatisfaction (BID) in burn survivors has a direct relationship with physical and psychological health related QoL.^{2, 13, 16} It has been found that body image mediates the relationship between pre and post-burn psychosocial function, thus adjusting to physical appearance changes is an integral component of adaptation and subsequent QoL following a severe burn.¹³ BID is therefore a potential quantifiable measure of psychosocial adjustment post-burn injury and QoL. Difficulties forming or maintaining social or sexual relationships are significant post-burn injury issues and the psychosocial effects of feeling socially marginalized and stigmatised, may lead to avoidance behaviour.^{17, 18} Avoidance of social activities limits the ability to meet a potential partner and develop an intimate relationship, and may result ultimately in social isolation. This is potentially due to societal influences to conform to stereotypical ideals of physical attractiveness being stronger for females in general.^{19, 20} Increases in depression have been found in burn survivors who have scarring in normally visible body areas compared to those with scarring in non-visible areas.¹⁷ Visibility of scarring has also been linked to social, occupational and sexual avoidance.^{17, 19} Research suggests that premorbid evaluations of the importance of appearance and attractiveness are strong predictors of body image concerns post injury.²¹ Lawrence et al.²¹ found that those who placed a higher value on the importance of physical appearance, were more likely to have

greater difficulties with post-burn adjustment and body image, than those who did not place importance on physical appearance. This study also found that females scored lower on measures of body-esteem appearance. In addition Bergamasco et al's.²² study of body image changes in burn survivors identified that females reported greater shame in body appearance compared with males, suggesting that the societal stereotypes regarding attractiveness may affect women more than men, Understanding body image disfigurement over time in burn survivors, as well as coping strategies relating to changes in physical appearance, have important implications to the potential impact of BID on sexuality and QoL in burn survivors,^{3, 16} and as such requires greater empirical research.

5.3.3 Aim of Study

The aim of this study was to investigate BSHS-B responses to identify whether burn survivors report negative changes in the sexuality and body image domains of this measure and whether these changes improve or deteriorate over time. As there is little research conducted on these QoL domains this is a preliminary study whereby understandings gained are intended to guide future research directions.

5.4 Methodology

Responses from collated BSHS-B questionnaires for the sexuality and body image domains were analysed. The data analysed was collected via the Burns Clinical Outcome Project (BCORP). This project was initiated in January 2006 at Royal Perth Hospital (RPH) to collect outcome data of all burns patients at hospital admission and hospital discharge as well as at one, three, six and twelve month time points post-burn injury. The aim of BCORP was to collect functional and QoL outcome measures from burn inpatients and outpatients, to devise evidence based treatment programs and develop strategies for medical, nursing and allied health burn rehabilitation.²³ Approvals for this study were gained the Curtin University Human Research Ethics Committee (HR 196/2008) and the Royal Perth Ethics Committee (EC 2009/108) (Appendix B).

BSHS-B questionnaires where there were missing responses for one or more of the 40 questions were excluded. Hospital admission BSHS-B data was not analysed as

this data potentially reflected responses of patients in a trauma state. It was therefore felt that this data did not reflect ongoing QoL issues.

5.4.1 Participants

The data set identified for inclusion to this study consisted of 362 individuals that had completed a BSHS-B during their rehabilitation at any or all of the time points discharge, 1, 3, 6 and 12 months post injury. Of the 362 individuals 268 were male and 94 were female. The mean age was 39 years. The average TBSA burned was 10.07% with burn size ranging from 0.25-65.00% TBSA.

5.4.2 Instrument

The BSHS-B is a 40 item questionnaire developed as an accurate measurement tool of functional and psychosocial QoL outcomes for burn survivors in the clinical setting.^{24,25} It consists of 40 items measuring nine sub-domains; Heat Sensitivity, Hand Function, Affect, Treatment Regimes, Simple Abilities, Work, Interpersonal Relationships, Body Image and Sexuality.²⁶ Each domain is internally consistent and can be used separately as a tool to assess the various sub-domains.²⁵

The BSHS-B questionnaire states that respondents are to answer the questions based upon how ‘each statement/question has been affected by their burn within the past 7 days’. Responses are recorded on a Likert scale with 0 indicating their burn has resulted in an extreme impact response and 4 indicating no impact (Table 5.1).

Table 5.1: BSHS-B Likert Response Scale

Extreme	Quite a Bit	Moderate	A Little Bit	None
0	1	2	3	4

The purpose of this study is to examine the responses to the questions relating to sexuality (questions 21-23) and body image (questions 24-27), therefore only these sub domains were used for statistical analysis.

5.4.3 Statistical Methods

All data were analysed using R version 2.8.1 statistical package. The data were split into separate data sets for each BSHS-B questions 21-27. Only data sets where patients had complete responses for these questions, as well as complete demographic details, were included in the analysis. Demographic variables tested were age, gender and TBSA of the burn and burnsite. Initially the burnsite was categorised according to four locations; lower limb (L_limb), upper limb (U_limb), face and trunk. For each question 21-27, at each time point, the following model was used to test for significance; Q2A response (at time point B) ~ Age at time of assessment + gender + TBSA + L_limb + U_limb + Trunk + Face. Due to low numbers of respondents, particularly those categorised as 'face only', burn sites were re-categorised according to the 'body half' location of the burn. These categories were defined as Lower body only, Upper body only, and both (i.e. burns to both upper and lower body). The above analysis was repeated using the formula; Q2A response (at time point B) ~ Age at time of assessment + Gender + TBSA + Bodyhalf.

Logistic regression modelling was used to establish which demographic variables were significant at each time point. Table 5.2 shows the negative coefficients to identify the significant associations of these variables.

Using the body half categories during modelling, 'Age' was consistently significant for the sexuality sub-domain (Q21- 23). However, 'TBSA' and 'Gender' were significant for the body image domain (Q24 – 27). Question 23 differed to the other questions during logistic regression modelling in that there were no consistent variables that appeared to be significant between discharge and 6 months post injury. Responses at each time point using the 'body half' categories were initially calculated according to total responses. These were further broken down according to gender to ascertain whether there were higher impact responses in females, as suggested in previously published burns related literature. Tables 5.3 and 5.4 summarise percentages of impact reporting for the sexuality and body image domains analysed according to total responses of males and females combined (T) and a gender breakdown (M= Males, F= Females). 'No' impact percentages on these tables indicates the respondents scoring 4 on the BSHS-B and 'Yes' indicates a

participant scoring some impact related to the corresponding question i.e. any score from 0-3 on the BSHS-B. The initial aim of this study was to identify whether or not burn survivor's report negative changes in the BSHS-B domains of sexuality and body image, therefore the tables 5.3 and 5.4 have been provided in yes/no format to demonstrate this research question. Gender based responses for each BSHS-B likert scale response at each time point were also analysed and will be discussed, however this data was too extensive to be condensed into a table form. The discharge time point indicates discharge from inpatient care. In this data analysis there were no participants that were still inpatients at the one month time point, therefore all one month responses are post inpatient discharge.

5.5 Results

Logistic regression coefficients showed that there were negative associations regarding 'Age' and the sexuality sub domain (Table 5.2). This coefficient indicates that the older the patient the greater the likelihood that the individual may report some level of impact (0-3) on the BSHS-B, for sexuality specific questions. Negative associations were also found between gender and TBSA and the body image sub-domain (Table 5.2). The negative gender coefficient indicates that females are more likely to have greater impact scores with body image questions 24-27. Furthermore the greater the percentage of TBSA injured, the higher the likelihood of reporting some level of impact scores for the body image sub-domain.

Table 5.2: Negative Coefficients for Variables at Each Time Point for Questions 21-27 Using Bodyhalf

Time point (n)	Discharge (145)	1 mth (205)	3 mth (162)	6 mth (119)	12 mth (88)
Q21	Age TBSA	Nil	Age	Age TBSA	Age
Q22	Age	Age	Age	Age	Age
Q23	Nil	Nil	Nil	Nil	Age TBSA
Q24	TBSA	Nil	TBSA	TBSA	Gender TBSA
Q25	TBSA	Gender	Gender TBSA	Gender TBSA	Gender TBSA
Q26	TBSA	Gender	Gender TBSA	Gender TBSA	Gender TBSA
Q27	TBSA	Gender	Gender TBSA	Gender TBSA	Gender TBSA
Gender was defined as '0' for male and '1' for females within dataset					

5.5.1 Sexual Arousal/Interest

Table 5.3 summarizes the responses for the sexuality sub-domain questions. 18.4% of patients reported that their burn had an impact to some extent on their sexual arousal, at 12 months post injury. Individual percentages for each likert scale points were 81.6% 'not at all', 5.8% 'little bit', 3.5% 'moderate', 5.8% 'quite a bit' and 3.5% 'extremely'. Sorting by gender indicated that sexual arousal difficulties affected males and females similarly, particularly at 6 and 12 months.

Additionally 21.8% of patients reported a degree of 'loss' in sexual interest at 12 months post injury. Higher percentages for loss of sexual interest were found in females across all time periods except 3 months where the rates were similar at 17.4% (male) and 16.7% (female).

A little over seventeen per cent (17.2%) of patients indicated changes in hugging, holding and kissing at 12 months post injury. Higher negative reporting in males that their burn affected these activities, compared with females, were found at all time points with the exception of 12 months. In contrast at 12 months post injury there

was a significant increase in females reporting a negative change in hugging, holding and kissing (12.3 % males, 31.8% females). Of the 31.8% of females who reported their burn impacted their ability to hug hold or kiss, 13.6% responded 'a little bit', 13.6% 'moderate', 0% 'quite a bit', and 4.6% 'extremely'. This data indicates that over time females may experience a greater negative impact regarding changes to intimate touch, which is an activity stereotypically associated with female intimacy. However, in the initial phases of rehabilitation higher negative reporting for this domain was found in males. Thus, screening for changes in intimate touch and the impact that this has on individuals intimate and familial relationships is important to consider for both males and females.

Table 5.3: BSHS-B Sexuality Domain Responses

Q21 – I feel frustrated because I cannot be sexually aroused as well as I used to															
Impact	Discharge			1mth			3mth			6mth			12mth		
	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F
(n=)	14	113	31	203	165	38	158	122	36	116	86	30	87	65	22
	4														
No (%)	82.	81.4	87.1	83.3	83.0	84.2	84.8	82.8	91.7	81.9	82.6	80.0	81.6	81.5	81.8
	6														
Yes (%)	17.	18.6	12.9	16.8	17.0	15.8	15.2	17.2	8.3	18.1	17.4	20.0	18.4	18.5	18.2
	4														
Q22 – I am simply not interested in sex anymore															
Impact	Discharge			1mth			3mth			6mth			12mth		
	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F
(n=)	14	113	31	203	165	38	157	121	36	116	86	30	87	65	22
	4														
No (%)	82.	83.2	80.7	82.8	84.2	76.3	82.8	82.6	83.3	84.5	87.2	76.7	78.2	80.0	72.7
	6														
Yes (%)	17.	16.8	19.4	17.2	15.8	23.7	17.2	17.4	16.7	15.5	12.8	23.3	21.8	20.0	27.3
	4														
Q23 – I no longer hug, hold or kiss															
Impact	Discharge			1mth			3mth			6mth			12mth		
	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F
(n=)	14	113	31	202	165	37	156	122	34	115	85	30	87	65	22
	4														
No (%)	86.	84.1	96.8	88.1	87.3	91.9	84.6	82.8	91.2	91.3	90.6	93.3	82.8	87.7	68.2
	8														
Yes (%)	13.	15.3	3.2	11.9	12.7	8.1	15.4	17.2	8.8	8.7	9.4	6.7	17.2	12.3	31.8
	2														
T= Total percentages (Male and Female), M= Male, F = Female															
No (%) = Percentage of participants scoring 4 on the BSHS-B (None) Yes (%) = Percentages of participants scoring 0-3 on the BSHS-B (combination of responses from little – extreme impact)															

5.5.2 Body Image/ Appearance

The body image sub-domain (Table 5.4) had higher impact reporting rates compared to the sexuality sub-domain. Additionally, the higher percentages of negative impact reporting for the body image sub-domain were relatively consistent across all time points analysed.

For all time points following discharge approximately 30% of patients (both male and female) reported some level of impact regarding question 24 “*Sometimes , I would like to forget that my appearance has changed*” (Q25). At 6 months post discharge the negative impact appears similar with 36.1% males and 36.7% females reporting some degree of negative impact regarding changes to their appearance. However, when further analysed according extreme impact percentages (i.e. those who scored 0 for this question on the BSHS-B), it was found that females had significantly higher severity levels (16.7%) compared with males (3.5%). In addition there was a significant increase in females reporting a negative impact regarding this question at 12 months post injury (45.5%), thus indicating that body image issues for women potentially increase over time.

Negative perceptions of others regarding the physical appearance of burn scarring were a significant issue. A gender breakdown of responses showed that the negative impact responses for females ranged between 59.1%-63.2% across the 1-12 month time points, which was the highest negative impact response amongst the BSHS-B questions analysed. Negative impact responses for men were also high with a range of 34.9%-41.8% across the same time points. The negative internalisation of the appearance of scarring to burn survivors (Q27), shows the second highest negative impact response with females ranging between 48.4% - 59.1% and males 36.0% - 38.1% across all time points. Whilst negative response rates were still relatively high for question 26 relating to individuals general appearance with 45.5% of females and 21.9% of males, reporting some level of negative impact 12 months post injury, these rates were lower than questions 25 and 27 which directly related to the appearance of the scarring itself.

In general, for all body image domain questions, the frequency of negative impact reporting and the severity of this impact increased between discharge and 12 months post discharge. This indicates that rather than body image perceptions improving as

physical function increases during rehabilitation, self-esteem and sexual esteem decreases within the burn population in terms of numbers of burn survivors experiencing decreased self and sexual esteem, and the severity of these negative perceptions.

Table 5.4: BSHS-B Body Image Domain Responses

Q24 – Sometimes, I would like to forget that my appearance has changed															
Impact	Discharge			1mth			3mth			6mth			12mth		
	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F
(n=)	14 5	114	31	203	165	38	158	122	36	116	86	30	87	65	22
No (%)	71. 7	69.3	80. 7	66.5	69.1	55. 3	68.4	67.2	72. 2	63.8	64. 0	63. 3	69. 0	73. 9	54. 6
Yes (%)	28. 3	30.7	19. 4	33.5	30.9	44. 7	31.7	32.8	27. 8	36.2	36. 1	36. 7	31. 0	26. 2	45. 5
Q25 – I feel that my burn is unattractive to others															
Impact	Discharge			1mth			3mth			6mth			12mth		
	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F
(n=)	14 5	114	31	203	165	38	158	122	36	116	86	30	87	65	22
No (%)	55. 9	55.7	54. 3	54.2	58.2	36. 8	55.7	60.7	38. 9	58.6	65. 1	40. 0	56. 3	61. 5	40. 9
Yes (%)	44. 1	44.1	45. 2	45.8	41.8	63. 2	44.3	39.3	61. 1	41.4	34. 9	60. 0	43. 7	38. 5	59. 1
Q26 – My general appearance really bothers me															
Impact	Discharge			1mth			3m			6mth			12mth		
	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F
(n=)	14 5	114	31	203	165	38	158	122	36	116	86	30	87	65	22
No (%)	71. 7	72.8	67. 7	71.9	74.6	60. 5	75.3	77.9	66. 7	73.3	76. 7	63. 3	72. 1	78. 1	54. 6
Yes (%)	28. 3	27.2	32. 3	28.1	25.5	39. 5	24.7	22.1	33. 3	26.7	23. 3	36. 7	27. 9	21. 9	45. 5

Q27 – The appearance of my scars bothers me															
Impact	Discharge			1mth			3mth			6mth			12mth		
	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F
(n=)	145	114	31	203	165	38	158	122	36	116	86	30	87	65	22
No (%)	61.4	64.0	51.6	58.1	61.8	42.1	58.2	62.3	44.4	61.2	66.3	46.7	59.8	66.2	40.9
Yes (%)	38.6	36.0	48.4	41.9	38.1	57.9	41.8	37.7	55.6	38.8	33.7	53.3	40.2	33.9	59.1

T= Total percentages (Male and Female), M= Male, F = Female
No (%) = Percentage of participants scoring 4 on the BSHS-B (None) Yes (%) = Percentages of participants scoring 0-3 on the BSHS-B (combination of responses from little – extreme impact)

5.6 Discussion

Results of this study support similar studies^{13, 14, 16, 27} indicating that burn injuries have a significant impact on sexuality and body image satisfaction for burn survivors.

Depression symptomologies, PTSD and medication side effects all have a negative impact on sexuality and sexual function,¹⁰ however, the extent to which biopsychosocial changes in sexuality impact burn survivors QoL has received little attention within both burns and trauma literature, potentially leaving many of these issues undiagnosed and untreated. Whilst further research is required to understand the full effect of these factors on sexuality changes in the burn population, this study does identify that sexuality following burn injuries is an area that warrants further investigation.

The sensitivity of the BSHS-B as an accurate screening measure for sexuality and body image related concerns is questionable. For example question 22 regarding loss of sexual interest is open to interpretation and as such the impact of burn injuries on sexual interest or arousal may be under reported. Due to social stigmatisation, burn survivors may experience difficulties in meeting an intimate partner and maintaining a satisfying sexual life. Whilst opportunities to engage in sexual activities may be limited, interest in participating in sexual activity may not be diminished. In the BSHS-B this may present as someone scoring that their burn has no impact on their interest in sexual activity, however difficulties in being able to express this interest may still be present. Additionally ambiguity in the terminology could also impact the responses. For example what does arousal or sexual interest really mean? Each patient may have different personal definitions of what sexual arousal is for them, thus without a context for reference respondents may score differently according to their own definitions.

Hugging, holding and kissing are often regarded as more important to female intimacy expression, however, results indicated that there were higher percentages of men reporting difficulties regarding these activities at all time points except 12months. At 12 months there was a significant increase in females reporting a negative impact (31.82%) compared with males (12.3%). Of the 31.82% of females who reported their burn impacted hugging, holding and kissing, more than half (18.19%) reported the impact as being moderate to extreme. This question in the

BSBS-B does not specify if hugging, holding or kissing is in the context of sexual activity or in the context of familial touch, therefore, it is impossible to ascertain if this question would produce different results depending on the context. It does however raise concerns regarding the impact that the burn has on the importance of touch as a means of bonding and intimacy in all relationships, and how this potential lack of touch has an impact on secondary elements such as increases in depressive symptomologies for both men and women post injury.

In general the results of this study indicate significantly higher negative impact percentages for questions that related to body image satisfaction (questions 24-27 of the BSBS-B). Question 25 '*I feel that my burn is unattractive to others*' had the greatest frequency of impact reporting for both males and females (Table 4). In addition the severity of the impact was generally greater in females. For example the percentages for males and females reporting an impact score at 12 months for question 25 was significantly higher for women (4.6% male compared to 27.3% female). This was similar for question 24 '*Sometimes, I would like to forget that my appearance has changed*' at 6 months post injury where impact response frequencies were similar (36.1% males and 36.7% females). However, when sorted according to gender the severity level of this impact appears to be significantly greater for females (16.67% females compared with only 3.49% of males) recording a '0' or extreme impact response. This finding is consistent with other reports on body image perceptions following burn injury. Studies indicate that females have greater difficulties adjusting to body image alterations following burn injuries which also have a direct impact on their self-esteem, depression symptomologies and sexual satisfaction.^{7, 17, 19, 28} Body image can be defined as the internalised mental picture one has of his/her body that is influenced by perceived societal stereotypes of physical attractiveness, health and function.^{29, 30} BID following burn injuries has been found to have a direct relationship with physical and psychosocial health post-burn.^{3, 7, 13} Fauerbach et al's¹⁶ study of BID on subsequent psychological and physical adjustment at two months post-burn injuries found that BID related to prolonged difficulties with physical and mental health related QoL, even after adjusting for premorbid QoL and injury severity. In this study the SF:36 physical subscale domains were lower in all burn survivors relative to published norms, however, adjustment in the SF:36 mental health domains was poorer only for those in the BID group.¹⁶ The most significant finding was that BID was found to be an

independent determinant of adjustment following a burn injury and as such is an important clinical determinant of psychological health related QoL.¹⁶ Thombs et al's¹³ longitudinal study of body image following severe burn injuries supports BID as a clinical indicator of QoL adjustment. The path analysis of their study found that BID was the most salient predictor of psychosocial function post severe burn at 12 months and mediated the relationship between pre and post-burn psychosocial function in women and those with greater TBSA of burn. In an earlier study by Thombs et al⁷ female gender, mediated by BID had a significant correlation with depressive symptomologies. Body image esteem was found to be lower in females compared with males, suggesting that issues relating to appearance and attractiveness have a greater impact on female body image.^{7, 13, 14, 30} The findings of this study are therefore consistent with the burn literature. Body image satisfaction/dissatisfaction has a role in mediating the relationship between pre and post-burn psychosocial function and adaption following a severe burn, which in turn affects overall QoL.

5.6.1 Limitations

The small sample size particularly in relation to female responses means a single extreme response could significantly alter the frequency percentages relative to the male responses. This however, reflects the nature of burn injuries where males are generally over-represented in the burn population due to factors such as high risk occupations and behaviours.²³

Outlier responses were also looked at, however due to the number of variables and the adjustments made to the 'burnsite' categories to deal with these variables for the statistical analysis, we were unable to accurately identify and plot the impact of outlier responses. Initial indications of this data suggest that outlier responses did not greatly impact the results. Whilst this is a limitation within the data analysis, this study has highlighted that this is an important consideration and as such future analysis will require more clearly defined 'burnsite' categories and robust analysis to further identify the impact of outlier responses.

There was a significant decrease in participant numbers for the 12 month and 24 month time frames, potentially inflating the negative reporting frequencies, especially for females. Finlay et al²³ conducted a study investigating poor attendance of patients at the Western Australia Burn Service clinic 12 months post

injury. The purpose was to assess the impact this has on outcome data that may then lead to improved services. This study reported that the drop off in clinic attendance was most likely related to a good physical recovery, especially in the younger, adult burn population, and not associated with dissatisfaction with the service or severity of burn injury. This study potentially indicates that many patients, especially with minor burns, do not attend follow up clinic appointments due to a good physical outcome. However, outcome measures such as the BSHS-B currently used in the Western Australian Burns Service are not specific psychosocial screening tools that accurately assess body image and sexuality. It is therefore not possible to say if there were potential ongoing body image and sexuality issues present for the clients included in Finlay et al's²³ study. The question remains open whether, they would have been likely to attend clinics beyond 6 months had body image and sexuality services been available. The BSHS-B responses analysed in this study were also analysed as part of Finlay et al's²³ study, thus, this study does potentially demonstrate that there are significant and ongoing issues regarding body image and sexuality, even if a good physical recovery is achieved. Further research of service need in these areas is required. Additionally due to the dropout rate of respondents particularly at the 12 month time point there were only 22 patients in this data set that had completed BSHS-B questionnaires at all-time points from discharge – 12 months post injury. As a preliminary study this data was not was not longitudinally analysed, however this is to be considered for further research.

Another potential limitation is that the body surface categories chosen for analysis were not specific enough. Previous burn research regarding sexuality suggests that female sexuality is significantly impacted when scarring is in visible locations such as the face.^{19,27} We were obliged to use the body surface categories as the data that had been collected over several years was not specific enough regarding scar locations. Future studies regarding sexuality and body image following burn injuries would benefit from having clearer body surface categories. These should include 'visible' and 'hidden' locations of scarring to examine the impact of scarring visible scarring vis a vis hidden.

5.7 Chapter Conclusions

Results show that sexuality and body image following burn injuries are important QoL domains that should be addressed during post injury rehabilitation. Whilst screening tools are available to address these issues, they are not routinely used within rehabilitation services due to service limitations including discomfort levels of staff, lack of appropriate training and lack of funding for equipment and resources to run appropriate programs.

Further empirical research regarding sexuality and body image in the burns population is required.

5.8 Chapter References

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Chapter 6: Sexuality, Body Image and Relationships Following Burns: Analysis of BSHS-B Outcome Measures.

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6.1 Chapter Introduction

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The inference from the previous strand of study presented in chapter five was that the preliminary data indicated that burn injuries have a significant impact on changes to sexuality and body image related quality of life, and that these changes are potentially long standing, particularly for females.

The preliminary data analysis indicated that further multivariate statistical analysis was warranted. The aim of this strand of study was to investigate statistical data analysis to test the hypotheses (derived from the previous data analysis inference), that a) burn survivors experience decreases in sexuality body image, affect and relationship related QoL, b) that these changes are present up to 12 months post injury and c) that females with larger burns are particularly at risk of issues relating to decrease quality of life within these domains.

6.2 Abstract

Objectives: The Burns Specific Health Scale – Brief (BSHS-B) was analysed to investigate the longitudinal impact of burn injuries on sexuality and body image.

Methods: Four sub-domains of the BSHS-B domains were of particular interest; sexuality, body image, affect and relationships, and as such were investigated for correlation between all of the subscales of the BSHS-B.

Results: A total of 1,846 observations from 865 Western Australian burn patient BSHS-B questionnaires were analysed. Descriptive statistical methods included dichotomous and ordinal scale variables and medians, as well as the range for continuous variables. Inferential statistical methods used longitudinal linear mixed-effects models and random effects models with the BSHS-B total and its subscales as dependent variables.

The four BSHS-B domains of interest all showed no significant change over time, indicating that the psychological and psychosocial impact of burn injuries does not significantly improve for burn survivors, regardless of good physical and functional recovery.

Conclusions: Burn survivors experience sexuality, body image and relationship changes following a burn injury, which may affect their quality of life (QoL) over time. Rehabilitation services need to be aware of these issues and create rehabilitation programs that specifically and meaningfully address these issues for burn survivors.

6.3 Chapter Introduction

The impact of burn injuries on sexuality and intimate relationships for burn survivors is under researched, thus many rehabilitation health professionals remain under confident and undertrained in working with these issues within the clinical setting.¹ Studies focussing on sexuality changes following burn injuries have indicated that burn survivors may experience decreases in sexual self-esteem, decreases in sexual and relationship satisfaction and higher rates of sexual dysfunction.²⁻⁴ A preliminary study of sexuality and body image following burn injuries conducted by Connell, Coates and Wood³ found that there were high percentages of sexual and body image dissatisfaction up to 12 months post injury, as measured by the Burns Specific Health Scale-Brief (BSHS_B). Dissatisfaction in the BSHS-B sexuality and body image domains were particularly prevalent in female burn survivors. This current study builds on Connell, Coates and Wood³ preliminary study by conducting further statistical analysis of findings from longitudinal BSHS-B outcome measures of WA burn survivors, to determine the impact of burn injuries on changes in sexuality, body image and relationships over time.

6.4 Methodology

6.4.1 Subjects

The subjects for this study were 865 burns patients treated by the Adults Burn Service of WA based at Royal Perth Hospital. Patients were eligible for the study if they had an inpatient admission to the Royal Perth Hospital Burns Unit and had at least one record of the brief version of the Burn specific health scale (BSHS-B) on at least one occasion after the burn injury. Patients who did not meet these criteria were not included in this study. The instrument was first used in 2001 and became routinely used from 2006 at hospital discharge, one month, three months, six months, 12 months post-burn injury. A total of 1,846 observations were available for analysis. Ethical approvals to conduct this research with Royal Perth Hospital patients were gained from the Curtin University Human Research Ethics Committee (HR 196/2008) and the Royal Perth Ethics Committee (EC 2009/108) (Appendix B).

6.4.2 Measure

The BSHS-B was used to analyse changes in sexuality, body image, affect and relationships over time. The BSHS-B is a 40 item questionnaire validated in the burns population to measure functional and psychosocial quality of life (QoL) outcomes for burns survivors.^{5,6}

There are nine internally consistent sub-domains measured by the BSHS-B; Heat Sensitivity, Hand Function, Affect, Treatment Regimes, Simple Abilities, Work, Interpersonal Relationships, Body Image and Sexuality.^{5,6}

Whilst other QoL outcome measures are also gathered from patients during their care at the above time points, the BSHS-B was chosen for this analysis as it specifically incorporates the target variables of potential changes to sexuality and body image within the assessment domains.

6.4.3 Statistical Methods

Descriptive methods included percentages for dichotomous and ordinal scale variables and medians plus the range for continuous variables. Inferential statistical methods used longitudinal linear mixed-effects models and random-effects models with the BSHS-B total and its subscales as dependent variables. Robust estimation of the standard error was applied because the BSHS-B scales were not normally distributed as indicated by the Shapiro-Wilk test. The assumption of linearity was assessed using restricted cubic spline transformations. Interactions between covariates and gender were assessed using multiplicative interaction terms. In addition to time the following covariates were assessed: Age (standardised), Total burn surface area (TBSA%), Burn depth (superficial, superficial partial, deep partial, full thickness), Gender, Burn site (upper limb(s) only, lower limb(s) only, upper and lower limb(s), trunk/torso, upper limb and trunk, face (with or without other body parts), lower limb and trunk, three or more body parts), Marital status (single (never married), Married, De facto relationship, separated, divorced or widowed), Burn agent (thermal, chemical, scald, contact, other) and Residential location (metropolitan, rural). The correlation between BSHS-B subscales was assessed using Spearman's rank-order correlation coefficient. A p value less than 0.05 was regarded as statistically significant.

All analysis was conducted using the Stata statistical package, Version 12 (StataCorp. 2011. *Stata Statistical Software: Release 12*. College Station, TX: StataCorp LP).

6.5 Results

Eligible patients had dates of injury from 26th February 2001 to 31st May 2012, with almost all injured from January 1st 2006 (96%). The median age was 35 years with a wide range from 13 to 87 years. Most patients were male (73%). Most patients had minor burns (<15% TBSA) with 63% having at least one surgical intervention and a median hospital length of stay of 8 days (range: 0-777 days), Table 6.1.

Table 6.1: Description of the Subjects

Variable	All eligible patients (N = 865)		Missing observations (n (%))
	Observations n = 1,846		
Dates of injury (first to last)	26 th Feb 2001	31 st May 2012	0
Age (median, range)	35 years	13 – 87	2 (0.23)
Gender (%)	male: 73.2%	female: 26.8%	1 (0.12)
Total assessments (n, %)	1846	100 %	
at 1 month post-injury	555	30.1 %	
at 3 months post-injury	403	21.8 %	
at 6 months post-injury	321	17.4 %	
at 12 months post-injury	262	14.2 %	
at 24 months post-injury	77	4.2 %	
TBSA(%) (median, range)	4%	0 – 75 %	32 (3.7)
Minor burn (<15% TBSA) (%)	82.9 %		32 (3.7)
Total LOS (days) (median, range)	8	0 - 777	101 (13.8)
ICU admission (n, %)	31	3.6 %	246 (28.4)
Surgical treatment (n, %)	521	63.0%	38 (4.4)
Anatomical site of burn (n, %)			63 (7.3)
Upper limb (UL)	176	22.0 %	
Lower limb (LL)	253	31.6 %	
UL & LL	121	15.1 %	
Trunk/torso	37	4.6 %	
Trunk + UL	80	10.0 %	
Trunk + LL	15	1.9 %	
Three or more sites (except face)	38	4.7 %	
Face (± other)	38	10.2 %	
Burn depth (n, %)			227 (26.2)

Superficial	38	6.0 %	
Superficial, partial	216	33.9 %	
deep, partial	272	42.6 %	
Full thickness	112	17.6 %	
Burn agent (n, %)			299 (34.6)
Thermal	323	57.1	
Chemical	35	6.2	
Scald	132	23.3	
Contact	62	11.0	
Other	14	2.5	
Marital status (n, %)			256 (29.6)
Single	309	50.7	
Married	217	35.6	
Defacto	49	8.1	
Separated	6	1.0	
Divorced/widowed	28	4.6	
Residential status			32 (3.7)
WA metropolitan	448	51.8	
WA Rural	170	19.7	

6.5.1 Control of Confounding Covariates

Table 6.2 identifies the significant associations between the BSHS-B sub-domains. Gender, age at burn injury and %TBSA are significantly associated with affect and relationships, sexuality and body image and thus provide an opportunity to confound any examination of the change over time.

Table 6.2: Significant Covariates for Selected BSHS-B Sub-scales – Univariate Mixed Model Analysis

Outcome scale	Possible covariate	Coefficient	95% CI		p
			LCL	UCL	
BSHS-B total	Mean over time	132.1	129.7	134.5	<0.001
	Gender: female (vs. male)	-8.16	-11.6	-4.67	<0.001
	TBSA%	-0.51	-0.66	-0.37	<0.001
	Burn site: Face (vs. upper limb)	-11.5	-17.4	-5.46	<0.001
	Burn site: 3 or more (vs. UL)	-9.61	-18.0	-1.26	0.024
	Burn depth (4 categories)	-3.00	-5.15	-0.85	0.006
	Burn agent: contact (vs. thermal)	-10.8	-17.3	-4.32	0.001
Affect & relationships	Mean over time	51.5	51.1	51.9	<0.001
	Gender: female (vs. male)	-1.45	-2.27	-0.63	0.001
	Age (standardised)	-0.75	-1.11	-0.38	<0.001
	TBSA%	-0.08	-0.11	-0.04	<0.001
	Burn site: Face (vs. upper limb)	-2.07	-3.51	-0.66	0.004
	Burn site: 3 or more (vs. UL)	-2.42	-4.42	-0.42	0.018
	Burn depth (4 categories)	-0.76	-1.27	-0.25	0.003
	Residence: rural WA (vs. metro)	1.08	0.13	2.03	0.025
Sexuality	Mean over time	11.1	11.0	11.2	<0.001
	Age (standardised)	-0.40	-0.50	-0.30	<0.001
	TBSA%	-0.02	-0.03	-0.01	<0.001
	Burn site: Face (vs. upper limb)	-0.64	-1.04	-0.25	0.001
	Burn site: Lower limb (vs. UL)	-0.33	-0.61	-0.04	0.024
	Marital status: widowed (vs. single)	-1.38	-2.60	-0.16	0.026
	Burn depth (4 categories)	-0.22	-0.36	-0.08	0.002
	Residence: rural WA (vs. metro)	0.32	0.06	0.59	0.017
Interpersonal relationships	Mean over time	15.2	15.1	15.3	<0.001
	Burn site: UL+LL (vs. upper limb)	-0.42	-0.74	-0.09	0.013
	Burn site: 3 or more (vs. UL)	-0.57	-1.10	-0.04	0.034
	Marital status: married (vs. single)	0.43	0.18	0.68	0.001
	Burn depth (4 categories)	-0.17	-0.30	-0.03	0.015
	Burn agent: contact (vs. thermal)	-0.48	-0.96	-0.002	0.049
Body image	Mean over time	13.4	13.1	13.6	<0.001
	Gender: female (vs. male)	-2.06	-2.47	-1.66	<0.001
	Age (standardised)	0.61	0.43	0.79	<0.001

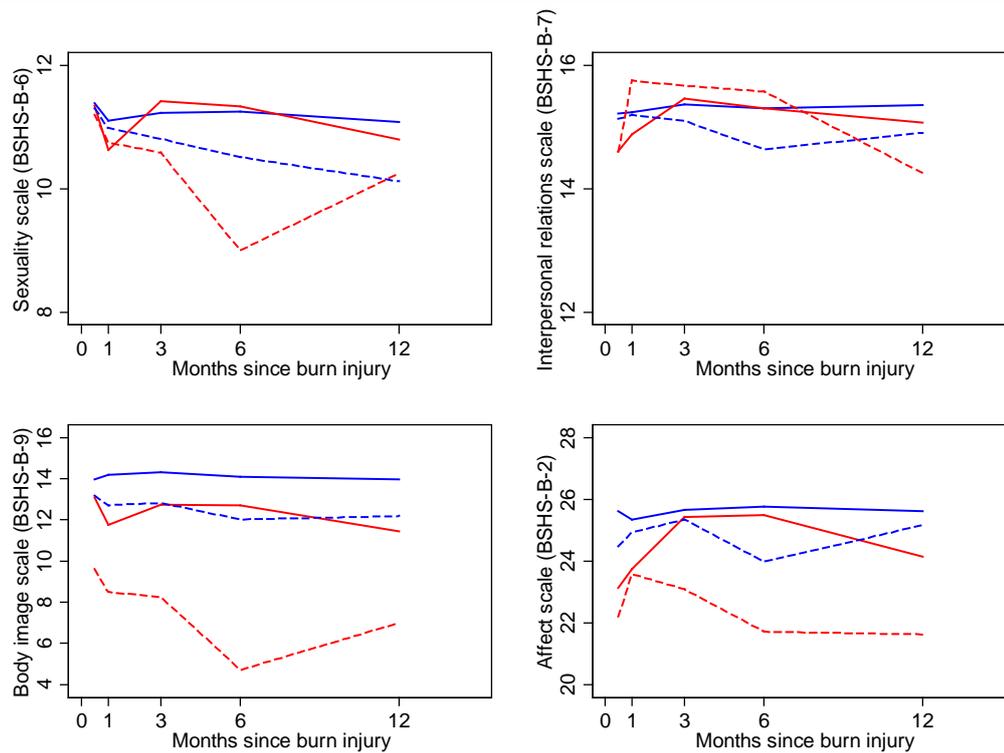
	TBSA%	-0.09	-0.10	-0.07	<0.001
	Burn site: UL+LL (vs. upper limb)	-0.72	-1.34	-0.11	0.021
	Burn site: Face (vs. upper limb)	-1.44	-2.15	-0.73	<0.001
	Burn site: 3 or more (vs. UL)	-1.28	-2.29	-0.28	0.012
	Marital status: married (vs. single)	0.99	0.51	1.46	<0.001
	Burn depth (4 categories)	-0.46	-0.72	-0.20	0.001
	Burn agent: Chemical (vs. thermal)	-1.62	-2.61	-0.64	0.001
	Burn agent: Other (vs. thermal)	1.84	0.13	3.55	0.035
	Residence: rural WA (vs. metro)	0.84	0.36	1.32	0.001
Affect	Mean over time	25.1	24.9	25.4	<0.001
	Gender: female (vs. male)	-1.12	-1.62	-0.63	<0.001
	Age (standardised)	-0.27	-0.49	-0.05	0.017
	TBSA%	-0.04	-0.07	-0.02	<0.001
	Burn site: Face (vs. upper limb)	-1.39	-2.24	-0.53	0.002
	Burn site: 3 or more (vs. UL)	-1.79	-3.00	-0.59	0.004
	Residence: rural WA (vs. metro)	0.61	0.04	1.19	0.037

Multivariable mixed model analysis for each scale of interest with significant covariates and any significant interactions with gender are provided in table 6.3. Time since burn was included as a linear and non-linear term and retained in the model if either term was significant.

For the BSHS-B total scores, age showed a significant interaction with gender so that age had a significantly negative association for men (coefficient = -3.7, $p = 0.007$) and a significant positive association for women (coefficient = 7.3, $p = 0.001$).

TBSA% was not different for men and women and showed a significant linear negative association (coefficient = -0.62, $p < 0.001$). For time since injury there was a significant interaction with gender. For women there was a linear positive association (coefficient = 5.4, $p = 0.006$) and for men a non-linear positive association (coefficient = 2.9, $p = 0.024$). The overall result of these associations and interactions is that women have a lower mean BSHS-B total score than men with less improvement over time for minor burns and a lower mean BSHS-B total score than men for major burns (Figure 6.1).

Figure 6.1: Change in Selected BSHS-B Sub-scales Over Time by Gender and Burn Severity



Legend: Blue = Men, Red = Women. Solid line = Minor burn, Broken line = Major burn.

The Sexuality sub-domain age also showed a significant interaction with gender with men having a lower score with increasing age (coefficient = -0.7, $p < 0.001$) and women having a higher score with increasing age (coefficient = 0.5, $p = 0.028$). TBSA% showed no interaction with gender and was associated with a linear reduction in sexuality score with increasing %TBSA (coefficient = -0.4, $p < 0.001$). The overall impact of these associations and interactions is that there is little difference between men and women and no change over time for minor burns but a greater deficit for major burns and a greater difference with gender and time since burn.

The interpersonal relations sub-scale showed that burn site was associated with a lower score for women for upper limb plus lower limb (coefficient = -3.4, $p < 0.001$) and facial burns (coefficient = -1.9, $p = 0.004$). The overall impact of the associations and interactions is that there is little change over time for men with minor burns, whereas there is a fall over the first six months following the injury and a possible recovery afterwards for men with major burns. For women there is a short-term

recovery for both major and minor burns from a low baseline score but a fall thereafter particularly for major burns.

There was a difference between men and women in the association between body image score and TBSA% with a lower reduction in the score with increasing TBSA% for men (coefficient = 0.6, $p < 0.001$) than for women (coefficient = 0.9, $p = 0.004$). Increasing burn depth was associated with a lower score similarly for men and women (coefficient = -0.3, $p = 0.028$). Burn site showed a significant interaction with gender, with men having a higher body image score for lower limb burns compared with upper limb burns (coefficient = 1.0, $p = 0.007$) and women showing lower scores for lower limb (coefficient = -1.9, $p = 0.012$), upper limb plus lower limb (coefficient = -4.2, $p < 0.001$), facial (coefficient = -3.8, $p < 0.001$) and three or more sites (coefficient = -4.5, $p = 0.004$). The overall impact of these associations and interactions is that women have much lower scores than men particularly if the burn injury is major. For men there is little change over time for minor and major burns whereas for women there is a fall in body image over time for the first 6 to 12 months which may be followed with some improvement.

The BSHS-B Affect subscale and the association with age is curvilinear negative with significant linear (coefficient = -0.9, $p < 0.001$) and non-linear components (coefficient = -0.6, $p < 0.001$) so that affect score falls with increasing age. TBSA% also shows a negative association with affect falling with increase size of burn (coefficient = -0.05, $p = 0.002$). For women whose marital status is separated there is a significantly lower affect score (coefficient = -13.9, $p = 0.003$) and for men there is a positive association with married (coefficient = 1.6, $p < 0.001$), de facto (coefficient = 1.7, $p = 0.008$) and separated (coefficient = 3.8, $p = 0.002$) categories.

Table 6.3: Multivariable Mixed Models for BSHS-B Total and Selected Sub-scales

Outcome scale	Covariates	Coefficient	95% CI		p	
			LCL	UCL		
BSHS-B total range: 0-160	Age (standardised) for men	-3.69	-6.39	-0.99	0.007	
	Age (standardised) for women	7.33	3.15	11.5	0.001	
	TBSA%	-0.62	-0.83	-0.41	<0.001	
	Time since injury (linear): for women	5.40	1.51	9.29	0.006	
	Time since injury (non-linear)	2.91	0.38	5.45	0.024	
	Burn site: men UL & trunk (vs. upper limb)	10.8	3.36	18.2	0.004	
	Burn site: women UL & LL (vs. upper limb)	-22.3	-36.9	-7.77	0.003	
	Face (vs. upper limb)	-26.6	-43.2	-9.97	0.002	
	Marital status: Married (vs. single)	6.29	1.28	11.3	0.014	
	De facto (vs. single)	9.64	2.43	16.8	0.009	
	Separated (vs. single)	16.9	2.04	31.8	0.026	
	Burn agent: for women Contact (vs. thermal)	-35.5	-49.8	-21.2	<0.001	
	Residence: men WA rural (vs. WA metro)	6.50	1.70	11.3	0.008	
	Residence: women WA rural (vs. WA metro)	-17.0	-27.6	-6.39	0.002	
	Constant	134.3	126.3	142.2	<0.001	
	Sexuality range: 0-12	Gender (women vs. men)	1.52	0.12	2.92	0.033
		Age (standardised) for men	-0.70	-0.91	-0.50	<0.001
		Age (standardised) for women	0.49	0.05	0.92	0.028
		TBSA%	-0.036	-0.051	-0.020	<0.001
Burn depth for women		-0.45	-0.85	-0.05	0.029	
Burn site: women UL & LL (vs. upper limb)		-1.52	-2.61	-0.42	0.007	
Face (vs. upper limb)		-1.95	-3.17	-0.74	0.002	
Marital status: men Married (vs. single)		0.84	0.43	1.26	<0.001	
De facto (vs. single)		0.83	0.21	1.46	0.009	
Separated (vs. single)		1.77	0.63	2.90	0.002	
Burn agent: men Other (vs. thermal)		-1.27	-2.32	-0.22	0.018	
Burn agent: women Other (vs. thermal)		5.29	1.69	8.88	0.004	
Residence: men WA rural (vs. WA metro)		0.36	0.01	0.72	0.041	
Constant		10.9	10.2	11.5	<0.001	

Interpersonal relationships range: 0-16	Age (standardised)	-0.36	-0.55	-0.18	<0.001
	Gender (Women vs. men)	0.94	0.05	1.82	0.039
	Burn site: women				
	UL & LL (vs. upper limb)	-3.41	-4.53	-2.30	<0.001
	Face (vs. upper limb)	-1.85	-3.09	-0.60	0.004
	Marital status: men				
	Married (vs. single)	0.70	0.28	1.11	0.001
	Burn agent: men				
	Scald (vs. thermal)	0.58	0.15	1.01	0.009
	Burn agent: women				
	Scald (vs. thermal)	-1.06	-1.85	-0.26	0.009
	Residence: men				
	WA rural (vs. WA metro)	0.47	0.11	0.83	0.011
	Residence: women				
	WA rural (vs. WA metro)	-1.00	-1.82	-0.18	0.017
Constant	14.8	14.4	15.2	<0.001	
Body image range: 0-16	Age (standardised) for women	1.09	0.36	1.82	0.003
	TBSA% for men	-0.055	-0.084	-0.026	<0.001
	TBSA% for women	-0.091	-0.153	-0.029	0.004
	Burn depth	-0.32	-0.61	-0.03	0.028
	Burn site: men				
	Lower limb (vs. upper limb)	0.97	0.26	1.68	0.007
	Burn site: women				
	Lower limb (vs. upper limb)	-1.85	-3.28	-0.41	0.012
	UL & LL (vs. upper limb)	-4.18	-6.00	-2.36	<0.001
	Face (vs. upper limb)	-3.83	-5.98	-1.68	<0.001
	3 or more sites (vs. upper limb)	-4.50	-7.58	-1.43	0.004
	Marital status: women				
	De facto (vs. single)	-3.04	-5.01	-1.07	0.002
	Burn agent: men				
	Chemical (vs. thermal)	-1.76	-2.77	-0.74	0.001
Residence: men					
WA rural (vs. WA metro)	1.17	0.58	1.76	<0.001	
Constant	14.3	13.4	15.3	<0.001	
Affect range: 0-28	Age (standardised) linear	-0.93	-1.28	-0.58	<0.001
	Age (standardised) nonlinear	-0.57	-0.85	-0.29	<0.001
	TBSA%	-0.045	-0.072	-0.017	0.002
	Burn site: women				
	UL & LL (vs. upper limb)	-3.68	-5.74	-1.61	<0.001
	Face (vs. upper limb)	-3.75	-6.00	-1.49	0.001
	Marital status: men				
	Married (vs. single)	1.55	0.76	2.34	<0.001
	De facto (vs. single)	1.71	0.44	2.98	0.008
	Separated (vs. single)	3.78	1.37	6.20	0.002
	Marital status: women				
Separated (vs. single)	-13.9	-23.0	-4.70	0.003	
Residence: men					

WA rural (vs. WA metro)	1.23	0.54	1.91	<0.001
Residence: women				
WA rural (vs. WA metro)	-1.94	-3.38	-0.50	0.008
Constant	24.6	23.8	25.4	<0.001

6.5.2 Correlation Between BSHS-B Subscales

There was a significant correlation between all of the subscales of the BSHS-B. The four subscales of Affect, Sexuality, Interpersonal relationships and Body image are all significantly correlated with each other with rank order correlations between 0.39 and 0.61 (Table 6.4(a)).

The association between the major subscale of Physical function (BSHS-B 11) and the four subscales of Affect, Sexuality, Interpersonal relationships and Body image was of particular interest. Table 6.4(b) shows the rank order correlation between each of the minor subscales and the function scale which indicates the association is positive and significant for all of the scales with rho greater than 0.3 for each scale.

Table 6.4(a): Correlation Between BSHS-B Sub-scales at First Assessment Post-burn

BSHS-B subscale	Spearman's rho	p
Affect x Sexuality	0.50	<0.0001
Affect x Interpersonal relationships	0.61	<0.0001
Affect x Body image	0.51	<0.0001
Sexuality x Interpersonal relationships	0.47	<0.0001
Sexuality x Body image	0.40	<0.0001
Interpersonal relationships x Body image	0.39	<0.0001

Table 6.4(b): Correlation Between BSHS-B Sub-scales and BSHS-B Function

BSHS-B subscale	Spearman's rho with BSHS-B Physical function	Adjusted regression coefficient*	p
Affect	0.42	0.198	<0.0001
Sexuality	0.31	0.071	<0.0001
Interpersonal relationships	0.33	0.072	<0.0001
Body image	0.32	0.117	<0.0001

* The coefficients are adjusted for age, gender, TBSA%, burn depth and time since injury.

6.6 Chapter Discussion

Some studies have indicated the potential impact of sexuality^{7,8} and body image⁹⁻¹⁶ changes in burn survivors; however, there are few that have investigated the long term effects of sexuality and body image of these changes over time. This study showed that burn injuries have a significant negative impact on sexuality, body image, affect and relationship aspects of QoL over time. The clinical significance of these results are that burn injuries may be continuing to have a negative effect on the quality of life of patients long after the potential discharge from rehabilitation services.

6.6.1 Sexuality

Tudahl and Blades⁷ were the first to look at sexual functioning and satisfaction in post-burn injury patients. Results indicated that there was no correlation between sexual dissatisfaction and males and as such the authors concluded that males appeared to have excellent post-burn satisfaction. Their results did however, indicate that females experienced lower sexual functioning which was also strongly correlated to body image and physical functioning. Additionally Tudahl and Blades⁷ did not find an association between TBSA % and differences in sexual satisfaction. In contrast this current study with the increased number of patients and episodes of data collection, found that there was an association between decreasing scores for the sexuality domain and increases in TBSA % for both males and females. In addition, whilst burn site location was not correlated with changes to sexuality in males, there was a correlation between lower sexuality scores in women and burn site areas of upper limb, lower limb and face.

Overall when looking at the mean score of respondents for the sexuality sub-domain in this current study, it did not initially appear that there were significant changes to sexuality for burns survivors over time (mean score 10.9 out of a possible score of 12). The sexuality sub-domain of the BSHS-B consists of only 3 questions and needs to be considered in association with other domains.³

6.6.2 Affect and Interpersonal Relations

When individually analysed, these two domains did not show any significant correlations or associations. However, Willebrand and Kildal ⁶ conducted a second order factor analysis of the BSHS-B which produced 3 internally valid scales from the 9 BSHS-B domains, of which Affect and Relationships was one of these scales. This scale was therefore used to investigate possible changes over time, which was found to be significant when adjusted for variables such as age, TBSA %, burn site, burn depth, gender and marital status.

Total scores for the Affect and relationship BSHS-B domains combined indicated that patients who were in a relationship prior to their burn injury scored higher than those who were not in a relationship prior to their injury. In addition, scores for these domains combined did not improve over time. In other trauma groups, such as spinal cord injury survivors, it has been found that those who were not in sexual relationships prior to their injury have greater difficulty forming or maintaining sexual relationships post injury.¹⁷⁻¹⁹ Our study indicates that this phenomenon is similar for burn trauma injuries in that those who identify themselves as single appear to have greater difficulty with the impact of their burn regarding the psychosocial impact of their relationship participation.

6.6.3 Body Image

Today's society places great emphasis on physical appearance, youthfulness and athleticism. Unfortunately the disfiguring nature of burn injuries is that individuals may experience negative changes in all of these areas. Results from this study indicated that body image changes do affect burn survivors and that these affects can be longstanding. Baseline scores for people with major burns were low (11.5 out of a possible score of 16) and over time this score did not improve. As with other body image related research ¹⁴⁻¹⁶ females appear to be particularly at risk of body image related dissatisfaction. Body image scores for females in this study decreased over the first 12 months and were then followed by some improvement; however, this improvement was not statistically significant. Furthermore, there was a significant correlation between females having lower scores for the body image domain of the BSHS-B and having burns to the lower limb, upper and lower limb combined and the face. This trend was also found with regard to the sexuality domain analysis. The

correlation for females with these particular burnsite areas indicates that there are potential issues for body image related dissatisfaction and visible scarring/disfigurement. This finding supports Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach¹⁴ longitudinal study assessing body image in burn survivors, where it was found that being female, TBSA % and the importance that one placed on appearance were the main indicators of body image dissatisfaction. The results of this current study also demonstrate that the psychological impact of the burn injury does not improve relative to gains in physical function. This finding further supports Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach's¹⁴ theory that psychological impact of body image dissatisfaction (BID) is a more accurate predictor of psychological function and QoL outcomes than physical function measures. Incorporating body image models such as Newell²⁰ fear-avoidance model of psycho-social difficulties following disfigurement and Price²¹ model for body image care during assessment and treatment is therefore essential to guide the individual treatment plans of burn survivors on an ongoing basis. Correlations between TBSA and gender found in this study are similar to those associated with post traumatic stress disorder (PTSD), therefore, it may be thought that PTSD may have affected our results. In our study the BSHS-B domain analysed that would have been most sensitive to effects of PTSD is the Affect domain. We did not find any correlations or associations within this domain when analysed independently. When combined with the Interpersonal Relationships domain we did find significant correlations with age, TBSA and marital status, however these associations were less significant than those found in the sexuality and body image domains. We conclude that although the pattern of response regarding sexuality and body image is similar, PTSD is not a primary factor affecting our results.

6.6.4 Physical Function Associations

Physical function improved significantly for all patients over time. This physical improvement may also correlate with the improvements found in the Work domain of the BSHS-B. However, although patients in this current study physically improved, the psychological and psychosocial elements of the burn injury did not improve over time. Whilst physical rehabilitation is highly important in the overall treatment and rehabilitation for burn survivors, this study showed that psychological

rehabilitation was important particularly from 6 months onwards post-burn injury. Unfortunately, as Rimmer, Rutter, Lessard, Pressman, Jost, James²² point out, healthcare practitioners are neither adequately trained or comfortable in addressing psychosocial issues that go beyond traditional physical and vocational rehabilitation.

6.6.5 Limitations

Not all patients completed BSHS-B questionnaires at all time points for this study; therefore, there are some potential issues regarding missing data. However, for the variables that were analysed within this study the missing observations accounted for less than 5% of the data, therefore missing data is unlikely produce a major selection bias and was not further analysed.

Multiple data sets were merged to gain the demographic data. There were some issues with the consistency with the burn site variable. This was adjusted for the purpose of this analysis, however, future outcome measure analysis would benefit from ensuring standardisation of demographic data such as burn site to improve generalizability.

6.7 Chapter Conclusions

This study showed that over time patients experienced increased difficulties in sexuality, body image and relationships which potentially affected their QoL post-burn injury. This deterioration in psychosocial elements of QoL occurred regardless of improvements to physical function. Therefore; rehabilitation services need to be aware of the potential impact of these domains and develop specific rehabilitation programs that can effectively assess and meaningfully respond to these changes. Whilst this is beyond the scope of this study, research into other trauma groups such as spinal cord injuries suggests that a contributing factor is the lack of inclusion of quality sexuality rehabilitation within our healthcare services. Whilst many studies have indicated that multidisciplinary health professionals recognise the importance of including sexuality, body image and relationships in rehabilitation services, personal comfort levels and lack of competence are contributing factors that prohibit these issues from being addressed as a matter of discourse. Furthermore, research is required in order to assess best practice for interventions, which can be delivered

within professional development for health professionals so that these issues can be addressed within the mainstream discourse of burn rehabilitation.

6.8 Chapter References

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Chapter 7: Burn Injuries Lead to Behavioural Changes That Impact Engagement in Sexual and Social Activities in Females.

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7.1 Chapter Introduction

This chapter is a post-peer review version of the above article currently accepted for publication and in press, in the *Journal of Sexuality and Disability*. Publisher copyright policies relating to this article are supplied in Appendix I. Co-author statements are provided in Appendix J.

The inference from the previous strand of study presented in chapter six was that the preliminary data indicated that burn injuries have a significant long term negative impact on changes to sexuality, body image and relationship related quality of life. These changes do not change generally do not improve over time, regardless of improvements in physical function. Females with larger burns are at great risk of experiencing body image dissatisfaction up to 12 months post injury. Conceptual framework

This strand of study aimed to gain an understanding of the ‘lived experience’ of the impact of burn injuries of females sexuality and body image issues and how these were addressed within the rehabilitation services that they received. Results from this study provide a conceptual framework for the behavioural changes that are associated with sexuality and body image changes for females.

7.2 Abstract

Objectives: Burn injuries are associated with significant changes to physical and psychological function. Little is known regarding the impact that burn injuries have on females' sexuality and how this in turn affects their relationships and body image. This qualitative study aims to add narratives of the lived experiences of female burn survivors to provide evidence that sexuality and body image changes are important indicators of post-burn adjustment and quality of life, which should be included as important components of post-burn rehabilitation.

Methods: This study included a phenomenological approach incorporating semi-structured interviews of 5 women with varying size of burn. The data collection and analysis was guided by Kvale's seven stages of interview inquiry.

Results: Burn injuries are life changing events that result in behavioural changes that impact engagement in sexual and social participation for females. These changes result in alterations to ones internalised concept of body image and attractiveness that have the potential to impact all facets of life. Findings from the thematic analysis in this study lead to the development of the Adjustment to Sexuality and Body Image Changes Post-burn Model. This model conceptualises potential body image and sexuality changes post traumatic injury and identifies possible areas for targeted interventions that could be incorporated into rehabilitation services.

Conclusions: Burn injuries are correlated with behavioural changes that have a potential adverse impact on sexual and social engagement for female burn survivors. Further research investigating treatment strategies for post-burn adjustment is required to translate to improvements in clinical service provision.

7.3 Introduction

Burn injuries are sudden life changing injuries that are associated with individuals having to cope with physical and psychological changes as a result of their potentially disfiguring injury.

Body image dissatisfaction (BID) was found to be a unique predictor of pre and post-burn psychosocial function.^{1,2} Of significance in this review was the proposition that there is a causal effect of body image on sexual satisfaction and sexual esteem in a 'normative' population,³ and that this causal relationship may also be a factor in BID and adjustment to sexuality changes in the burn survivor population. Of significance in this review was the proposition that there is a causal effect of body image on sexual satisfaction and sexual esteem in a 'normative' population,³ and that this causal relationship may also be a factor in BID and adjustment to sexuality changes in the burn survivor population.⁴

Studies of body image and sexuality following burn injuries have found that survivors experience increased difficulties with body image satisfaction, sexual satisfaction, forming and maintaining relationships. Connell, Phillips, Coates, Doherty-Poirier and Wood's⁵ previous statistical analysis of Burn Specific Health Scale-Brief (BSHS-B) responses found that deterioration in these domains continued to occur over time, regardless of improvements in physical function. Additionally baseline scores for the BSHS-B body image domain were low (11.5 out of 16), with scores for females decreasing over a 12 month period. A correlation was found between low body image scores and having burns in potentially visible areas of the lower limb, upper and lower limb combined, and the face. Whilst these findings provide quantitative (QUAN) evidence that burn injuries impact sexuality and body image in females, there have been no recent studies looking at providing the lived experience of changes for women in these domains.

A literature review was conducted by the authors to investigate the impact of burn injuries of body image and sexuality changes for burn survivors.⁴ This literature review found that there was little research conducted in the area of sexuality and body image following burn injuries, and of the few articles sourced there was only one⁴ that investigated both of these variables.

On the basis of previous QUAN analysis and the evidence from the literature we proposed two hypotheses. Firstly we hypothesised that women who have sustained a

burn injury will have a correlate between decreased body image and sexual esteem. Secondly we hypothesised that body image and sexuality are inadequately addressed within many rehabilitation services.

To test these hypotheses a phenomenological approach was used to provide evidence of the lived experience of female burn survivors.

The objective of this study is to add to the body of evidence that there is a relationship between sexuality and body image changes in burn survivors and that this relationship is an important indicator of post-burn adjustment and quality of life that should be an important component of post-burn rehabilitation.

7.4 Methods

This study used a qualitative (QUAL) phenomenological approach which was intended to provide a greater understanding of the lived experience of burn injuries for adult females. A phenomenological approach was deemed most appropriate as it seeks to understand, describe and interpret the experiences of individuals who have all experienced a particular phenomenon,^{6,7} in this case the phenomenon being a burn injury.

7.4.1 Sampling

Purposive sampling was used to gain the depth of information regarding the experiences generated from individual cases of women who have sustained a burn injury. The first purposive sampling technique involved typical case sampling.⁸ Individual cases that represented the typical burn injury and recovery were approached via the WA Burn Service outpatient clinic. Secondly a snowball sampling approach was utilized where the first author was informed of appropriate cases from other medical, nursing and allied health team members within the WA burn service.

7.4.2 Participants

The inclusion criteria were females >18 years of age who had at least one attendance at the WA burn service outpatient clinic within the study timeframe. Only participants over the age of 18 years were included as they did not require additional guardian consent.

During the study period 20 women were approached to be included in this study. Of the 20 female patients approached 8 agreed to be interviewed for this study and 12 declined. Three potential participants were not able to be contacted to complete the interviews within the study timeframe, thus the final sample consisted of 5 women who consented to a semi-structured interview (Table 7.1).

Four of the participants in this study had sustained their burn injury between 1-4 months at the time of their interview. One participant had sustained her initial burn injury 11 years prior, however had undergone surgical dermabrasion for the treatment of her hypertrophic scarring 2 weeks before her interview and was undergoing outpatient follow-up, thus met the inclusion criteria.

There were no age or cultural exclusion for this study, however, all participants who consented were Australian and of Caucasian descent.

Table 7.1: Participants Included in Interviews With Demographic Information

Participant	Age at time of burn	Age at time of interview	Time post-burn	TBSA	Location of burn	Burn agent	Burn depth
P1	16	27	11 years	1%	Chest	Chemical	Deep partial
P2	25	25	3 months	49%	Face, neck, front and back torso, bilateral hands and upper limbs	Accelerants and Flame	Deep partial
P3	22	23	1 month	2%	Lower limb	Contact	Partial
P4	18	19	6 months	14%	Face, neck, Breast/chest, bilateral hands and upper limbs	Flame	Deep partial
P5	18	19	3 months	4%	Hip and lower limb	Contact	Deep partial

7.4.3 Data Collection and Analysis

Data collection and analysis was guided by Kvale’s seven stages of interview inquiry; Thematizing, designing, interviewing, transcribing, analysing, verifying and reporting.⁹⁻¹¹

Thematizing and design

The design and thematic identification stages of this study were conducted concurrently. The purpose of this study was to provide an understanding of the lived experience of female burn survivors with regarding to their sexuality and body image changes to provide insights that could be used to provide a greater understanding of QUAN outcome data analysis at the Burn Service of WA.

Semi-structured interviews were most appropriate for this study design as they allowed the researcher to elicit information to provide narrative to confirm or refute themes identified in earlier QUAN data analyses as well as allowing participants to elaborate on their experiences to gain a greater depth of understanding.⁷

Data Collection

The interviews were conducted between June 2010 and June 2012. The first author of this study conducted all of the semi-structured interviews included in this study. Three interviews took place in a quiet clinic room within the Burn Service of WA outpatient clinic, one interview was conducted in a quiet office at Curtin University and the final interview was conducted via telephone. The semi-structured interviews were between 40-90 minutes duration and were audio recorded via an iPhone or iPad. All audio recordings were transcribed by the first author verbatim.

Interviews began with structured open ended questions asking participants to narrate their current experiences of their burn injury. These open ended questions were designed to allow participants to express their experiences and understandings of their burn injuries in their own words.⁷ As the interviews progressed fixed questions were discontinued to allow the researcher to utilize active listening skills to ask more probing questions. Approvals for this study were gained from Curtin University Human Research Ethics Committee (HR/196/2008) and the Royal Perth Hospital Ethics Committee (EC 2009/108) (Appendix B).

7.4.5 Transcribing and Analysing

The authors analysed the data using a multi layered interactive approach to the data as described by Creswell's⁶ Data Analysis in Qualitative Research process. Raw data transcripts along with field notes were organized and prepared. Coding and theme identifications were performed by the principle researcher and a research assistant separately and then discussed and refined once this process was completed. During this process the data was read and re-read to gain a sense of the general tone of the data that was generated and notations made accordingly with regard to these impressions. Creswell⁶ describes coding as organizing data into bracketed chunks that are represented by a segmented category. This coding process was used to generate descriptions of the participant's sexuality and body image changes and the people, places or rehabilitation events that had an impact on these changes. These descriptions along with the identified codes formulated themes for further analysis. The themes identified were then analysed for each participant's transcript as well as across other participant's transcripts to develop commonalities of the lived experience to formulate a greater understanding.

7.4.6 Verifying

A triangulation process was used as a validity strategy during the data analysis. Creswell ⁶ recommends that qualitative researchers incorporate cross checking procedures to provide evidence of consistency within their results. Cross coding was initially conducted through intercoder agreement of codes and initial themes. These codes and themes were then verified by examining the evidence from previous quantitative studies conducted regarding sexuality and body image at the Burn Service of WA. Lastly an ongoing process of verifying the codes and themes through expert member checking was used to determine the accuracy of the findings. Four main themes were verified by the member checking panel of experts (Table 7.2).

7.4.7 Reporting

Making an interpretation of the findings and results based upon comparisons of the findings relating to burns published literature and previous QUAN data analysis was the seventh and final step that is presented in this paper.

Once the coding process was completed the principle researcher advanced the themes identified into a model of findings, bringing together the participants descriptions and themes. To represent how these findings may be used to affect change clinical the Adjustment to Sexuality and Body Image Changes Post-burn Injury Model was formulated. This model is discussed later in this paper.

7.5 Results

It was observed through both text and filed notes regarding tone and body language, that regardless of the size of the burn, all participants experienced an adverse change in how individuals perceived themselves with regard to their appearance and in turn this had a direct impact on their sexuality. These changes were independent of burn agent, total body surface area (TBSA) or burn dept. All participants described a gradual adjustment process to their new sense of self which was potentially prolonged through limitations in rehabilitation service provision. The four main themes extrapolated from the data along with their relevant subthemes are outlined in Table 7.2.

Table 7.2: Themes and Subthemes Describing the Experiences of 5 Participants with Regard to Their Sexuality and Body Image Post-burn Injury.

Theme	Subtheme
Body image dissatisfaction	<ul style="list-style-type: none"> * Visible vs. hidden scars * Decreased body image and self-esteem * Importance of pre-burn appearance
Changes in sexual esteem and satisfaction	<ul style="list-style-type: none"> * Behaviour modification during social activities * Behaviour modification during sexual activity
Adjustment to post-burn body	<ul style="list-style-type: none"> * Reactions of others * Impact on daily life
Reflections on burn care addressing sexuality and body image	<ul style="list-style-type: none"> * Perceptions of service provision * Impact of treatment regimes * Suggestions for the future

7.5.1 Body Image Dissatisfaction (BID)

Studies investigating the psychosocial impact of scarring in females have described body image as the mental image that an individual has of their own body, which is influenced by perceived and internalised societal stereotypes.^{12, 13} Body image dissatisfaction (BID) relates to the impact of dissatisfaction with appearance which is often experienced by burn survivors.^{2, 14, 15} Burn literature indicates that females report greater psychological distress, shame and depressive symptomologies following burn injuries compared to males and as such are at greater risk of developing BID.^{1, 2, 16, 17}

7.5.1.1 Visible vs. Hidden Scars

Research findings have been contradictory regarding the impact of the visibility of scarring and psychosocial adjustment. Orr, Reznikoff and Smith¹⁸ research investigating body image, self-esteem and depression in adolescents and young adults did not find a correlation between TBSA or location of scarring, with predictions of greater self-esteem and body image dissatisfaction. Likewise Heinberg, Fauerbach, Spence and Hackerman¹⁹ concluded that body image distress and dissatisfaction did not correlate with TBSA when investigating psychological decision making processes in undergoing reconstructive surgery post-burn injury. In

contrast, Connell, Phillips, Coates, Doherty-Poirier and Wood⁵ have previously found that there was a higher correlation between lower scores in the body image and sexuality domains measured by the BSHS-B and body surface areas identified as lower limb, upper limb plus lower limb and facial.⁵ These body surface areas could be potentially viewed as visible areas for scarring on the body that may not be easily covered by clothing. Participants in this current study described a discomfort with having their scars visible to others. Some indicated that they were adjusting well because they could 'hide' their scar, but stated that they would have adjustment issues if this was not the case. One participant with a larger burn had a very strong reaction to the visibility of her scarring.

*“Yeah its gut wrenching. I don't have any clothes after I take my garments off that will cover that s**t [referring to her scar].” (P2)*

Those who were able to cover their scars expressed a sense of relief that they could hide their scars from being viewed by others.

“I was always grateful it was somewhere where I could hide it [the scar], because like yeah it would be horrible not to be able to hide it.”

And later adds.

“Yeah but I don't think I'll ever be comfortable, you know wearing a top that showed it [the scar]. So obviously it's going to affect me the rest of my life, even though I don't think about it, that's only because I can put it out of my mind by covering it.” (P1)

7.5.1.2 Decreased Body Image and Self-esteem

Females following burn injuries are particularly at risk of dissatisfaction with body image esteem and self-esteem.^{2, 4, 5, 20} These negative impacts have been found to be longstanding.⁵ Participants in this study all indicated that there had been a change in how they felt about themselves, for example:

“...I have a shaved head, I have short tennis ball brown hair, I have scars all over my face, I have no eyebrows, my neck is pulling my face down, and the scarring means I have no jawline, and I have no proper smile, it’s like it’s bigger but it’s not proper and my body’s yuck [tearful] and with everything every day, it’s like every day is like Groundhog Day. EVERYDAY [emphasised] dressings and OT then Physio.” (P2)

One participant tearfully stated that she felt her partner left her because of her post-burn appearance.

“He says no [pause] but I know different.” (P4)

Others indicated that they felt differently about themselves than they did before, felt different to their peers and/or were unable to participate in social activities with their peers.

“ Um I was pretty [much] a mess at the beginning cause, it’s you know affected like my life in a lot more ways than I would have like expected when it originally happened, um, I was upset because of the look [of her scar] obviously and then like, I’m not allowed to go into the sun and there are so many things that like my friends were going to festivals and stuff so I was really upset about that and yeah so it was more like unattractive I guess yeah.” (P5)

There was also sense of grief or loss expressed in relation to the perception of the new sense of self in comparison to their pre-burn body image and sexuality. This was more strongly expressed in terms of analysis of tone and prevalence of this theme within the transcripts of participants with larger burns.

*“Of course! There’s nothing sexy about it and on top of it underneath I know is f**king disgusting. I look in the mirror and catch myself in the mirror and I cry all the time. I see my reflection in the car and I just think ‘oh I am a monster’, [tearful pause] I feel like I’m a monster.” (P2)*

7.5.1.3 Importance of Pre-burn Appearance

Thombs, Notes, Lawrence, Magyar-Russell, Bresnick and Fauerbach’s² longitudinal study of body image of survivors who had sustained severe burn injuries found that

there was a correlation between the importance an individual placed on their appearance pre-burn injury, the incidence of post-burn body image dissatisfaction. This phenomenon was identified within the transcripts of this study in two ways. Firstly some participants talked openly about how they felt about themselves prior to their burn. They described being comfortable with their appearance pre burn as they reminisced.

“Right so prior to my burn I was probably the most comfortable, I was, my sexuality was my thing and I was independent and fiercely independent and that was my sexuality. And I loved the way I looked... Obviously anything that I didn’t like I worked on which means it builds confidence when you work on something and you achieve your goal.” (P2)

Secondly, one participant provided further insight by indicating that her feelings about her post-burn appearance were influenced by her perceptions of others with disfiguring disabilities prior to her injury. This indicates that there is a potential for burn survivors to internalise their pre burn perceptions of disfigurement and projects these perceptions into their post-burn body schema.

“Um I wouldn’t go out in public. I think a lot of people would like say before my burn happened if I was to see like that in public I would probably look twice and I would feel like that, what people will do to me and I feel a bit uncomfortable about that.” (P5)

“So thinking about how you might have looked at someone with a scar...what would you have thought?” (Researcher)

“Um I’d probably would have looked back and looked a bit like ‘argh’ like that sort of thing.” (P5)

The lived experiences identified in this study under the theme ‘body image dissatisfaction’ verify Connell, Phillips, Coates, Doherty-Poirier and Wood’s⁵ findings that females with burn injuries experience decreases in body image satisfaction over time which is impacted by the visibility of scarring and their internalised body image esteem. Additionally evidence suggests that the importance of appearance an individual has prior to their burn injury should be identified as a

potential screening tool for anticipating body image dissatisfaction post-burn injury.
2, 5, 17, 21

7.5.2 Changes in Sexual Esteem and Satisfaction

7.5.2.1 Behaviour Modification During Social Activities

Most of the participants described some form of behaviour modification particularly in relation to social and sexual activities. Some participants indicated discomfort during social encounters with peers of whom they may have attraction to. This theme was predominantly expressed by those who were single or had been single for a period of time post-burn, in relation to social and sexual encounters.

“... you don't mess around with people because you have to show it [the scar] to them so you only really ever consider serious relationships where you get to know them and then you say 'oh you know I got like something to tell you', so you can't really have a one night stand or anything like that because you're too self-conscious about it.” (P1)

Connell, Phillips, Coates, Doherty-Poirier and Wood⁵ statistical analysis of BSHS-B responses found that those who identified themselves as single had greater difficulty adjusting to the psychological impact in relation to their burn injury on their relationship participation. The findings in this current study provide greater understanding to this statistical analysis. Participants described difficulties coping with social situations and initiating new relationships for fear of the reaction of potential partners to their burn scarring.

7.5.2.2 Behaviour Modification During Sexual Activity

In addition to avoiding social situations many participants indicated behavioural changes to their intimate sexual activity as a result of their burn injury. Changes included a decrease in the frequency of sexual activity and changes to their sexual repertoire. Additionally participants also indicated that it was difficult to 'shut off' thoughts and feelings about their burn during sexual activity and to cope with this they modified their sexual behaviour and environment to avoid their partner seeing

or touching their scar. This often resulted in them experiencing less sexual pleasure during the activity.

“Yeah I wouldn’t um want to just have sex naked like in the open, ‘cause I just wouldn’t feel comfortable and I think it would be a turn off... I would just think it [the scar] was really ugly and I would feel bad and I’d be stressing about if he was going to touch it would he feel sick.” (P5)

Whilst all participants stated that there were mainly negative changes to their sexuality post-burn injury, one participant noted that there was also a potential positive element to changes in her sexual activity.

“... I think before the accident I was a little too easy, so in a way there’s sort of been a semi positive, I can look at it in a positive way that it’s made a little like step back a little and I’ve more settled down to one person sort of thing, yeah.” (P5)

Whilst this potential positive lifestyle change was only expressed by one participant, it was included as a sub-theme as it was deemed to provide a new and significant insight that may warrant further investigation in future research.

Burn injuries have been associated with decreases in sexual satisfaction and esteem in female burn survivors.^{5, 17, 22} This study provides narrative to these empirical findings in that these changes in sexual satisfaction and esteem result in behaviour changes during social and sexual activities.

7.5.3 Adjustment to Post-burn body

7.5.3.1 Reactions of Others

The impact of unsolicited comments, questions and noxious staring on burn survivor’s adjustment and coping post-burn injury is under researched. Bergamasco, Rossi, Amancio and de Carvalho’s¹⁶ phenomenological study of body image in burn survivors found that more than half (n=20) of the participants (N=35) reported negative interpersonal consequences of their burn in the form of strangers staring, making comments and making jokes about their disfiguring scarring. They conclude

that socializing with others post-burn injury and dealing with the reactions of friends, family and colleagues can provoke fear for survivors. If the individual is exposed to negative reactions in the form of facial expressions, comments or ridicule from family or acquaintances, this may confirm negative perceptions of self that the survivor may already have, and thus further solidify these cognitive distortions. Fear in relation to the anticipation of reaction of others was expressed by all participants in this study.

*“Yeah, my girlfriend comes around all the time and she bought her boyfriend and in the past he used to say ‘you’re girlfriend [patients name] she’s the hottest’ [referring to herself] and used to tell his mates ‘see how she’s gorgeous blah’. And he came in and went ‘oh’ and his face just....my heart felt sunk [tearful]. I sunk to the bottom of the ground and I knew that I looked like that but.... I knew people were going to react like that. All my friends have been really good, they and family, but in my mind that’s what I thought people were going to react like they did and it’s not often I’m wrong and it’s so f***ed, it was so sad [tearful].” (P2)*

“Yeah one of my friends still stare at it, and he knows what happened, but it’s like he can’t help but look at it, so that makes me kind of uncomfortable.” (P1)

For some participants, whilst they anticipated a negative reaction to their scars, the impact of the actual reaction of others was less affecting than they had imagined.

“Yeah I need to build up and go ‘oh god what am I going to tell them.”

She continues further on in her interview to say in reference to the reactions of others with regard to her burn located between her breasts;

“...but every guy that I have ever been with has told me that I’m concentrating on the wrong part of the story, they don’t look between my tits.” (P1)

Bergamasco, Rossi, Amancio and de Carvalho ¹⁶ noted in their study that although burn survivors were faced with the cruel effects of stigmatization, they showed great resilience to these reactions in the form of understanding, humour, forgiveness and

the ability to block out the rudeness of others. This resilience was also evident within the voices of the participants involved in this study. Whilst there are situations that participants continued to have difficulty with, some identified that they had come to terms with other situations, such as innocent curiosity from young children.

“Nah I just like don’t mind little kids staring, but when you get the oldish people staring then you kind of say something to them and then different nationalities tend to steer more than others.” (P4)

7.5.3.2 Impact on Daily Life

Research regarding other trauma related disabilities has found that there are significant psychological impacts associated with the loss of function and requiring clinical handling of one’s body for the purposes of personal activities of daily living²³. This theme was identified within the transcripts of the participants in this study supports evidence from other trauma related disability research. Similar to other research, participants described an adjustment process to having people touch their bodies in areas associated with intimate touch for the purposes of personal care and dressings. On the whole this adjustment was difficult and was associated with a significant impact to an individual’s sexuality and self-esteem.

“Asking for and getting and needing help makes me feel like a cripple and the worst part was when I had to get my arse wiped. There’s no sexuality there I’ll tell you right now, if you could feel the opposite to sexy, that would be it and when you have to ask for help all the time like to eat, pull your pants up when you go to the toilet.”

Additionally, one participant who has visible facial scarring stated that her burn injury has a major impact on her ability to gain employment in the beauty profession. Although the appearance of her disfigurement in an industry based on societal stereotypes of beauty had not been cited as a reason for not gaining employment, there was a sense that this was a major contributing factor. Instead this participant had been told that she was unable to gain employment due to insurance purposes, however this had not been fully investigated by the participant.

“There’s been changes [pause] I didn’t go to ...I finished my studies of what I was doing last year. And just trying to find a job it’s hard to find a job in the industry that I was studying in... because apparently insurance is high in case I burn myself again and all that kind of stuff.” (P2)

“What’s the impact for insurance?” (Researcher)

“I’m not too sure, they haven’t said, but he said like ‘cause I have a burn injury if I like burn myself again with wax and stuff I might not be covered in the insurance.” (P2)

For this client her burn injury resulted in unemployment, which had a significant impact on her financial situation. Whilst this client became too tearful to discuss this issue further, literature from other trauma group cohorts has indicated that financial limitations associated with having a disability can have a significant impact on an individual’s quality of life. These limitations are not only in terms of being able to support one’s self with the basic necessities of life, but to afford extra items required as a result of their disability. In the case of a burn survivor this might be additional costs for items such as wigs and cosmetics that help to camouflage their scar. Whilst these are items that may help improve an individual’s sexual and body image, they are not funded through government assistance.

7.5.4 Reflections on Burn Care Addressing Sexuality and Body Image

7.5.4.1 Perceptions of Service Provision

When questioned if sexuality and body image issues had been addressed adequately during rehabilitation most participants stated that these topics were not asked or addressed during their treatment.

“No not even a mention of it. And I think that that’s the thing that I wouldn’t say angry, but most disappointed at.” (P1)

Another participant pointed out that during outpatient follow up clinics she was regularly given questionnaires that had sexuality and body image related questions, however although she indicated on these measures that she was having issues, in the

hope that this would be addressed by the burns team, this did not occur. This highlights a potential issue that whilst outcome measures might be taken routinely to evaluate service outcomes such measures give patients the expectation that domains covered will be addressed by the service. When this does not occur patients may experience a sense of disappointment with the burn service and are left to cope with these significant issues on their own. With reference to completing a BSHS-B questionnaire one participant states:

“Yeah. I did that and the first time I did that I was pretty, like, upset and so my answers were pretty upset and I thought. Like, they kept saying there was a psychologist and I thought, like, maybe I was going to be seeing her but, like, I didn’t hear anything about it.” (P5)

When asked which health professionals they would feel most comfortable discussing sexuality and body image issues with the doctors, nurses and occupational therapists (OT’s) professionals were identified as the most appropriate based on the ongoing nature of the contact with these health professionals during their rehabilitation.

“Probably the OT, only because they deal with you more on a long term basis and also because you can’t even think straight when you are in treatment like if a doctor says something to you like you know in 6 months make sure that you do this, you wouldn’t even hear it, you’re just concentrating on being alive.” (P1)

7.5.4.2 Impact of Treatment Regimes

The major aims of rehabilitation post-burn injury is for patients to achieve maximum independence, with minimum restriction from the effects of pathological scarring on their physical and psychological functioning.^{24, 25} Best practice to prevent excessive scarring post-burn injury involves a long process including a number of rehabilitation interventions including, functional mobility training, occupation based interventions and scar management regimes.

All patients involved in this study were actively receiving scar management treatment. Pressure garments were worn at some point by all participants involved in this study, with 4 of the participants still undergoing active pressure garment therapy at the time of the study. Pressure garment treatment in particular prompted the

strongest responses from participants with regard to their physical and psychological engagement in sexuality related activities of daily living. The overall tone prevailing from the transcripts was that participants found pressure garments had a negative impact on how they felt about themselves in terms of their femininity and sexuality.

“Every day is the same, I have to wear the same outfit that also gets you in the frame of mind, lower like in self-evaluation because you know when you wear a new outfit you feel sexy.” (P2)

Participant 2 adds insight with regard to the impact of having visible facial scar management treatment, in the form of face masks, on the expression of her sexuality. She highlights a potential dilemma that exists regarding the importance of pressure therapy for improvements to physical function and appearance, and the psychological effects of the treatment itself. She highlights that scar management treatments have a significant adverse effect on an individual’s sexual and self-esteem, to the point of contributing to decreases in self-esteem and quality of life.

“Like I was proactive about my sexuality and I think the costumes are kind of cool, you could make it cool, there’s nothing else we can do about it. Some of the things in OT that we have to wear like the mask, like it’s not sexy at all and can’t ever be because you face is sexuality.” (P2)

Ripper, Renneberg, Landmann, Weigel and Germann²⁵ qualitative study of adherence to pressure garment therapy found that the main reasons for non-compliance with treatments were perceived lack of information about pressure garment therapy, the need for regular replacement garments due to rapid wear and tear, dealing with negative reactions from the public and frustration with the long term wearing process that is involved in the remodelling of scar tissue. Whilst all participants in this study were compliant with their pressure garment regimes, similar frustrations with the rehabilitative scar management treatment was echoed in the voices of the transcripts. Further research and development of scar management treatments that do not add to the negative outcomes that burn survivors have to deal with post injury requires more attention.

7.5.4.3 Suggestions for the Future

All participants indicated that sexuality and body image issues should be incorporated as a standard procedure within burn rehabilitation.

“I think so because it could be something if you don’t feel kind of sexy and good in yourself well then you’re more likely to get depressed and all of that could lead to more kind of issues of it’s not addressed early.” (P3)

In general participants were happy for all members of the rehabilitation team to be involved in addressing their sexuality and relationship issues; however the occupational therapist was identified more frequently due to the long term relationship that they have with participants during their pressure garment treatment.

“Well maybe you’ve got to get someone in like, that’s kind of part of OT because that’s like rehabilitation and that is where you talk about sexuality and those experiences and stuff like that.” (P2)

“Yeah as a patient I’d be happy discussing those issues with either who I have the most contact with at the time so when I was having the initial dressings being done probably nurse, but now the Physio’s or OTs I’d be comfortable discussing it with.” (P3)

Ways in which sexuality and body image issues could be addressed were identified as posters in waiting areas and having staff initiate conversations regarding sexuality and relationship issues during clinical contact.

“Maybe, maybe you could make up some posters or something like with how are you feeling and that kind of stuff that people can sit there in that corridor quite a lot [referring to the outpatient waiting area] just up on the wall and have a look at an people might actually then when they sit there think actually ‘yeah it is a bit of an issue at the moment’ and so they might bring it up when they go in to see someone.” (P3)

7.6 Study Discussion

This research was guided by two hypotheses. Firstly we hypothesised that women who had sustained a burn injury would have a correlate between decreased body image and sexual esteem.

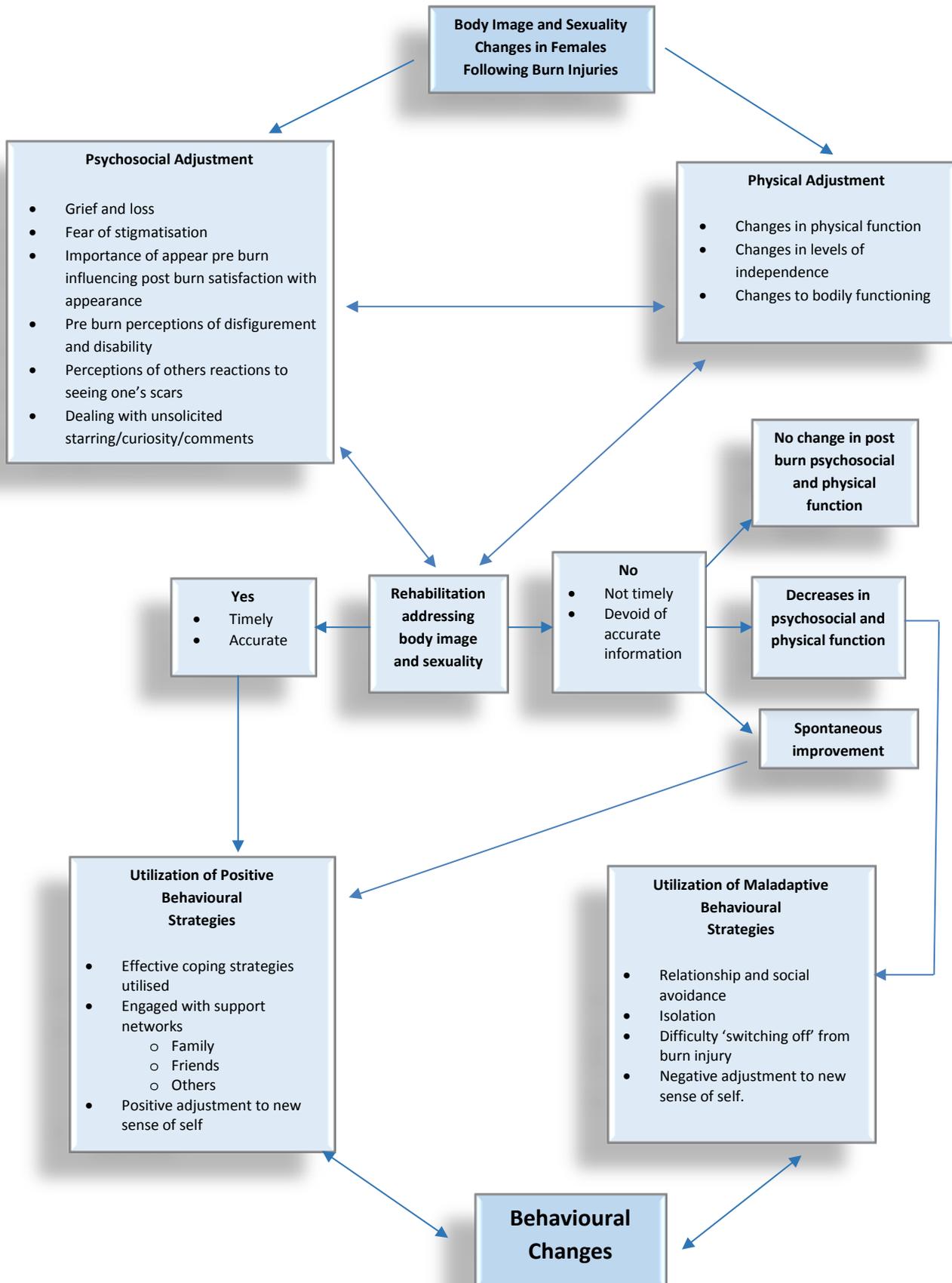
This hypothesis was confirmed in this Western Australian based cohort of female burn survivors. Participants in this study indicated that burn injuries are indeed life changing events that results in changes to how one internalises their concept of body image and attractiveness. As a result of these changes there is an adjustment process to a new sense of self that involves a slow integration of allowing others to view or touch ones scar. Central to this process is the internalised perception that scarring is unattractive to others, which lead all participants to exhibit behavioural changes in social and sexual situations.

Secondly we hypothesised that body image and sexuality are inadequately addressed within rehabilitation services. Across the interviews there was a sense that, in the absence of any specific rehabilitation regarding changes in body image and sexual esteem, there was a gradual process of coping and adjustment that survivors go through to deal with their new sense of self and particular in response to the reactions of others. All participants demonstrated resilience with respect to their situation which in turn was expressed as a certain amount of optimism that their quality of life as well as their appearance was going to improve over time. Whilst this resilience was present it was acknowledged by all participants that sexuality and body image should be a standard issue that must be addressed within burn care service provision. Interpretations of the findings of this study based upon continual reading of the transcripts and field notes, comparisons of the transcripts and comparisons of the finding with the body of literature on burns related sexuality and body image, led to the development of the Adjustment for Body Image and Sexuality Changes Post-burn Model. This model was developed to conceptualise the findings of this study in a way that demonstrates the important interconnections between psychological and physical function, the impact that rehabilitation may have on behavioural strategies. The central premise within this model is that, regardless of whether rehabilitation is provided or not, there are behavioural changes that occur regarding sexuality and body image as a result of a burn injury. Whether this behavioural change is positive

or negative will depend on the availability of quality, targeted rehabilitation to assist individuals to utilize positive adaptive behavioural strategies (figure 7.1).

The significance of this model is that it aims to provide rehabilitation services working with trauma survivors to conceptualise potential body image and sexuality changes post traumatic injury and identify possible areas for targeted interventions that could be incorporated into rehabilitation services to address psychosocial adjustment to disfiguring trauma injuries such as burns. To this end this model may be of use in multiple trauma contexts where survivors experience long term physical impairment and or visible disfigurement, rather than burns alone.

Figure 7.1: Adjustment to Body Image and Sexuality Changes Post-Burn Injury Model



7.6.1 Study Limitations

The main limitation to the present study is the small sample size of participants. Due to the sensitive subject matter of the interviews many of the potential participants approached did not consent to being involved in this phase of research. Although only 5 participants were interviewed, these participants represented the range of burn survivors that are treated at the WA Burns Unit in terms of variety of burn size, location and time post-burn. In addition, the Satisfaction with Appearance (SWAP) scores were compared between those who participated in interviews versus those who did not, to address possible selection bias. There was no significant difference between the average scores for those who participated in the study (38.2) compared with those who did not (32.7).²⁶ As such we believe that this research adds valuable information of the lived experience of female burn survivors, of which there is currently very little information.

In addition another limitation to this study is that we did not conduct follow up interviews or perform a series of interviews over a longitudinal period. Once again due to the sensitive nature of the topic we investigated and the difficulties encountered with recruitment for these interviews, it was deemed more appropriate to conduct a single interview only. Participants were, however, given the researchers contact details and encouraged to make contact to provide additional information if they wished to post interview.

Lastly, there were no participants over the age of 30 years old that consented to be part of this study. This may limit the findings in terms of potential experiential changes across the lifespan. However, young adults are particularly at risk of sustaining a burn injury, thus we feel that the inclusion of participants between the ages of 19-27 years represents an important cohort of female burn survivors.

7.7 Chapter Conclusions

Findings from this study indicate that there are potential issues for sexuality and body image and related dissatisfaction with the presence of visible scarring/disfigurement.

Whilst the holy grail of burn research is to develop a means of scarless healing, until this is achieved survivors are faced with coping with significant changes to their pre burn physical, psychological and psychosocial health. Continued research

regarding adjustment to sexuality, body image and scar management that can be translated into improvements in clinical service provision and the appearance of physical scarring, is needed to aid clients to have the best quality of life outcomes possible post-burn injury.

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Chapter 8: Summary, Discussion and Recommendations

8.1 Overview of Thesis

This study used an SMM research design approach to investigate the impact of burn scarring on women who have sustained a burn injury. Firstly, this study aimed to explore the extent to which trauma impacts sexuality and quality of life outcomes in female burn injury survivors, secondly it aimed to identify how sexuality is currently being addressed within rehabilitation services and lastly it aimed to identify the need for sexuality issues to be addressed as a matter of discourse within burn rehabilitation services.

To achieve these aims this research was conducted as a series of sequential studies using QUAN and QUAL approaches, with the insights gained from each study phase informing the methodology and interpretation of the subsequent studies. As there has been little research conducted in the area of sexuality following burn trauma, the initial literature review study phases were important in providing relevant background information. The first literature review investigated sexuality changes in terms of the broader context of trauma injuries. Whilst there may be differences in the pathophysiology of varying trauma injuries, they share some similar characteristics such as coping with the suddenness of a trauma event and associated injuries, adjustment to physical changes and changes in life roles as a result of injury. This literature review found that there were sexuality changes that could potentially be applied across all trauma groups, including burns. If not addressed in an adequate or timely manner, these changes can lead to long term physical and psychological consequences which include cognitive genital disassociation (CGD), sexual disenfranchisement (SD) and decreased desire to engage in physical sexual activity. All of which can have a significant negative impact on satisfaction with current relationships and/or difficulties with forming new relationships.

The second literature review was conducted to look specifically at the impact of burn injuries on sexuality and body image within the burn population. Previous literature review suggested that these two variables are intrinsically linked. What this second literature review found was that there was very little research regarding the impact of sexuality changes on burn survivors, and that most of the research conducted was

limited to case study evidence or studies with few participants and/or were conducted at one time point only. In contrast there has been more research conducted with regard to body image changes following burn injuries and most significantly this research strongly suggests that dissatisfaction with body image post-burn injury is both an important and unique indicator of post-burn adjustment that should be routinely screened for with in burn rehabilitation services.

The third study phase was a preliminary data analysis of BSHS-B outcome data gathered at the RPH Burn Unit of Western Australia (WA), to investigate the incidence and prevalence of sexuality and body image issues within the WA burn population. Findings of this study confirmed that sexuality and body image changes post-burn injury significantly impact their QoL outcomes over a 12 month period. This preliminary data also confirmed the hypothesis generated from the literature, that the effects of these changes are more severe in female burn survivors. This statistically generated inference guided the methodology and variable selection for further multivariate statistical analysis that was conducted in the fourth phase of this research.

The fourth study conducted was a longitudinal retrospective analysis of BSHS-B outcome measures. Due to the sequential nature of the research previous strand of investigation assisted the formulation of this larger and more in-depth analysis. At the time this study phase was conducted a larger database of participants was available allowing for multivariate analysis of a number of variables with the target BSHS-B domains. This study is significant not only in that it is the largest of its kind to be conducted within a burn population, but it provides longitudinal evidence that burn injuries have a negative impact of sexuality and body image changes on burn survivors, and that these changes have a long term effect on individuals QoL, particularly female burn survivors.

The last study phase was to understand the lived experience of female burn survivors. Using a qualitative approach, participants were able to provide valuable insights into their personal experiences of their internal concepts of sexuality and body image, how these have changes as a result of their burn injury, the impact that others have on these internal perceptions of themselves and the impact that rehabilitation services may or may not have had on adjustment to these changes. As a result of the thematic analysis of the participant interviews, the Adjustment to Sexuality and Body Image Changes Post-Burn Injury Model (figure 7.1.p 133) was

developed to assist health professionals to conceptualise potential sexuality and body image changes post traumatic injuries such as burns, and to identify possible areas for rehabilitation services to target interventions related to psychosocial adjustment following traumatic injury. It is hoped that whilst this model has been developed on the basis of burn research, the concept of this model will have relevance to other non-burn related trauma areas.

Due to the SMM approach to this research, chapters presented in this thesis are individual studies in which the research questions guiding each phase were influenced by the inferences and knowledge gained from the previous phases of study. As such each study has been presented in this thesis as in individual, published research article with their own research question, hypothesis, methodology, data collection and analysis. This concluding chapter provides an exegesis of the findings of all strands of this research combined, and how they come together to advance the body of knowledge with regard to sexuality and body image changes for females who have sustained a burn injury.

8.2 Discussion

This study is unique in that it investigates the phenomena of sexuality changes in women with burn injuries over time, which has not been done previously. In addition, by using a SMM research approach the study has been able to statistically prove that sexuality and body image issues are significant for women, regardless of the size of their burn injury. Through one-on-one interviews, it gives voice to their thoughts, feelings and challenges with regard to adjustment to their physically altered bodies.

8.2.1 Females are Vulnerable to Long Term Sexuality and Body Image Changes

Findings from the series of studies included in this thesis support the original hypothesis that females are particularly vulnerable to sexuality and body image dissatisfaction post-burn injury.¹⁻³

The preliminary data analysis indicated that there were high frequency rates of reporting negative consequences as a result of burn injury in the sexuality and body image domains of the BSHS-B in both males and females.² However, when analysed according to gender and severity of response on the BSHS-B Likert scale, the

severity of impact was significantly higher for females, especially with regard to the BSHS-B body image domain.² This finding informed the next strand of this research where it was deemed that further analysis of the BSHS-B data with particular emphases on investigating correlations between multiple variables was required to provide some predictive information to guide future rehabilitation approaches. Further in depth statistical analysis revealed stronger evidence that female burn survivors experience greater dissatisfaction with regard to their sexuality and body image changes following their burn injury as opposed to male burn survivors. In the case of major burn injuries female BSHS-B body image satisfaction baseline scores were low at the first data collection time point on hospital discharge (11.5 out of a possible score of 16). Of most concern is the finding that these scores had only marginal improvement at 12 months post injury, indicating that dissatisfaction with one's sexuality and body image post-burn is long standing and present regardless of improvements in physical function. Whilst BSHS-B scores were not as low in females with minor burn injuries compared with females with major injuries, there was relatively little change in these scores at the 12 month time point, indicating that body image and sexuality issues also have a significant impact on females with minor burns. The implications of these findings are that, regardless of the severity of burn injury, females are at risk of sexuality and body image changes and that these changes may result in long term dissatisfaction with their self-esteem and relationships. The results also suggest that the critical time for these changes is between 6-12 months post-burn injury, thus need to be considered particularly within outpatient rehabilitation programs.³

The phenomenology based QUAL strand of research conducted for the purposes of this thesis provided the 'lived' voice to the QUAN data. All participants confirmed that their burn injury had a significant impact on their body image satisfaction, relationship participation, socialisation and comfort levels during sexual activity.⁴ Participants frequently expressed fear and distress with regard to their scars being visible to others. There was also high distress indicated with family, friends or partners touching the burn scar area. The impact of real or perceived stigmatisation is complex and multidimensional. The role that society plays in the acceptance of those who do not 'fit' with the perceived physical 'norms' and the factors which perpetuate non acceptance such as media, are beyond the scope of this study. However, the notion of feeling stigmatised as a result of a burn injury resulting in

avoidance of social or sexual activities was evident throughout this study. Further research incorporating broader factors of stigmatisation for burn survivors is required. The challenge with this future research is that it needs to include cultural and societal influences along with investigating effective ways for individuals to adjust to stigmatisation, which is an external entity.

These findings do, however, provide evidence that sexuality and body image are essential domains of concern for burn rehabilitation clinicians that need to be screened for and addressed with individual treatment programs.

8.2.2 The Impact of Rehabilitation on Adjustment to Sexuality and Body Image Changes

The results of all phases of study, in combination, clearly demonstrate that sexuality and body image changes post-burn injuries are significant issues that should be addressed as a matter of discourse within burn rehabilitation. Moreover, when screened appropriately, these two issues in combination have a potentially unique and important role in the identification of overall quality of life post-burn injury.^{1,3,5} Unfortunately at this present point in time there is no validated tool sensitive enough to screen for these domains in the burn survivor population.

However, if such a tool was validated and available for use in the burn care setting, it may be seen as ethically inappropriate to be screening and identifying the need for intervention with regard to these domains, if there are not adequate services provided to do so. All participants in the QUAL phase of this thesis indicated that they had not been spontaneously approached by clinical staff with regard to how they were adjusting to changes in their sexuality and body image. In addition, the impact on how these changes were potentially affecting their personal relationships was also neglected. An example of this issue was outlined in chapter 7 of this thesis, where one participant noted that she had been given outcome questionnaires throughout her treatment at the RPH burns unit which included questions regarding her feelings towards her sexuality and body image. She stated that in giving her such questionnaires she interpreted this as being an indication that a clinician would review her responses and pick up on the difficulties that she was having in these domains, which would precipitate some form of response such as a referral to psychology services. She expressed disappointment that this did not happen, and

indicated that this had a negative impact on her recovery. This is an important reminder that whilst screening tools may be available to identify potential areas of difficulty for our clients, this information is redundant if it is not viewed and acted upon by clinicians. Having said this, it is also imperative that there are services available to which clinicians may refer patients. This study demonstrates that there is a definite need for specific and timely rehabilitation with regard to sexuality and body image changes post-burn injury and that addressing these issues will have a positive response on the quality of life of burn survivors. However it is the author's position that clinical services with specifically trained clinicians to address such issues are not currently available. Future research regarding the cost / benefit analysis of incorporating targeted sexuality and body image adjustment post injury is required as an extension of the research findings of this thesis.

8.3 Recommendations for Clinical Practice

Results from this research provide conclusive evidence that sexuality issues should be incorporated within individualised rehabilitation programs for burn survivors. Whilst this should be provided to all burn survivors, the findings indicate that females are particularly vulnerable to the impacts of negative changes to their sexuality and body image over time.

The first literature review of this thesis advocates broadening the definitions of sexuality within rehabilitation research beyond physiological sexual function, to incorporate intimacy, pleasure and variability in sexual expression. It is proposed that research based on improving clinical practice must incorporate the universally accepted World Health Organisation's (2002)⁶ working definitions of definitions of sex and sexuality. Using consistent language in clinical evaluations and research will assist understanding of both the positive and negative influences upon sexual and body image changes for trauma survivors.

It is recommended that burn units adopt an ethos that promotes a holistic approach to patient care, whereby patients understand that it is appropriate to approach the healthcare professionals within the team regarding these issues without fear of rejection. Additionally, the timing of when health professionals address issues of a sexual nature is a crucial consideration within rehabilitation treatment planning and an ethos forming process.⁷ Trauma survivors may initially experience CGD, whereby

sexual exploration is not a priority compared with functional ADL tasks essential for discharge from hospital and reintegration to the home and workforce.⁸ As such the initial phases of rehabilitation may be too early to comprehensively address issues of changes in sexuality; therefore it is essential that sexuality services be available on an ongoing basis as part of outpatient services^{7,9} However, this is a key time in which the ethos of acceptability can be fostered so that from the initial stages of their treatment, patients gain the understanding that the healthcare professionals involved in their care are willing to listen to their concerns regarding their life post-burn injury, including sensitive issues such as those associated with sexuality and body image changes.^{7,9} Comprehensive sexual rehabilitation should be advocated on an outpatient basis. Additionally, it is essential to provide a culture within acute rehabilitation services that acknowledges sexual issues as part of the 'normal' domain of concern addressed by healthcare staff. This culture must be present during initial contacts with medical, nursing and allied health staff, to decrease potential fear of the reactions of staff inhibiting patients from asking questions about their sexuality during future outpatient rehabilitation contact.^{7,9} In addition it has been found that post hospital discharge, individuals may develop a greater understanding of their physical and sexual changes, that can be addressed more realistically within outpatient sexual counselling and rehabilitation services,⁹ provided the patient can still access these services over time.

The PLISSIT model developed by Annon,¹⁰ has been used as a framework for health professionals working with patients to help identify their role in the assessment, evaluation and interventions of sexuality issues, within their own comfort and knowledge levels.¹¹ The acronym PLISSIT describes the four sequential levels of health professional intervention: Permission (P), Limited Information (LI), Specific Suggestions (SS) and Intensive Therapy (IT). Unfortunately, there has been a lack of appropriate education regarding the PLISSIT model, which has led to poor use in the sense that; a) that it is often presented a linear process with each level following sequentially¹² and b) there is a tendency for health professionals in practice to eliminate the permission level.¹¹ This elimination of Permission-giving to discuss sexuality can be seen in the instances where patients are supplied with an information booklet regarding potential changes to their sexuality, with the assumption being that by providing written information (i.e. providing limited information) the patient would raise sexuality matters to an appropriate professional. Thus permission is not

only implied and not explicitly given, but patient silence is potentially misinterpreted as a sign that sexuality matters are not an issue for them.¹¹

To address the misuse of permission giving within Annon's¹⁰ PLISSIT model, the Ex-PLISSIT model was developed by Taylor and Davis.¹² As an extension of the Annon's original PLISSIT model, the Ex- PLISSIT model emphasises that Permission-giving is at the core of each phase of this model. All levels and interventions begin with explicit Permission-giving, allowing individuals to have the opportunity to discuss issues, ask questions, normalise and challenge concerns that they might hold regarding changes to their sexuality.^{11, 12} In addition, the Ex-PLISSIT model promotes a learning cycle for health professionals of reflection and review to challenge assumptions and to develop knowledge, skills and self-awareness¹²; thus making it a potentially useful tool for all health professionals working in trauma rehabilitation. Whether it is the PLISSIT or the Ex-PLISSIT model that is used, it is essential that staff are trained to use these models in a manner that promotes explicit permission at all levels, enables them to take appropriate actions in a professional and non-judgemental way, and indicates to the patient that it is more than acceptable to discuss sexual matters during the course of their treatment. Development of specific sexuality and body image training programs for burn rehabilitation staff needs to be implemented as a starting point for a change in the ethos of rehabilitation unit's staff. Incorporating specific sexuality and body image information as outlined in the Adjustment to Sexuality and Body Image Post-burn Injury Model in Chapter 7 along with strategies such as the PLISSIT or Ex-PLISSIT models into staff training would provide frameworks and knowledge for staff to improve their attitudes, knowledge, skills and comfort levels when addressing such emotionally laden facets of life for burn survivors. Additionally, providing the opportunity for staff to professionally develop their knowledge, skills and attitudes towards sexuality and body image issues within the clinical setting will provide a foundation for further extension of client centred clinical practice with in burn unit settings.

8.4 Recommendations for Future Research

Further research regarding the impact of trauma injury on sexuality is required to improve QoL outcomes for trauma survivors. There are potential commonalities amongst trauma groups regarding the negative impact that sexuality changes have on QoL post trauma injury, however, there is a significant disparity in the amount of empirical research amongst individual trauma groups, thus making it difficult to generalise research findings in order to suggest improvements to rehabilitation services as a whole.¹³ This disparity needs to be addressed within both trauma and sexuality studies in order to make practical improvements to the QoL of all major trauma survivors.

There is little or no continuity with regard to sexuality definitions, research methodologies, measures and scales within both sexuality and trauma studies, resulting in fragmented research, lacking empirical evidence.^{14, 15} Standardisation in methodologies would be conducive to being able to generalise information across trauma groups, thus potentially adding greater depth to a limited body of knowledge.^{14, 15}

The majority of the background literature and empirical studies on the topic of sexuality and body image in trauma groups were based upon heterosexual activity. Therefore, a broadening of the concept of sexuality being inclusive of diverse sexualities is required, if there is to be movement towards truly holistic rehabilitation services.

The benchmark in current healthcare trends is to provide holistic services aimed at enhancing individuals QoL post trauma, however, the exclusion of sexuality from activities of daily living further reinforces an asexual stereotypes regarding people with disabilities.⁸ This is perpetuated by the non-inclusion of sexuality related components within the domains of many of the outcome measures used in trauma rehabilitation, such as, the SF: 36, which is regarded as the ‘gold standard’ measure of health related QoL within rehabilitation services. As the research evidence from this study suggests, functional limitations impacting sexual activity as a result of trauma have a direct relationship on secondary psychological effects such as depression, PTSD and social isolation; thus reinforcing the need for sexuality to be included in diagnostic tools, outcome measurement data and rehabilitation programs. Further empirical research to validate appropriate screening tools is required in order

to improve individualise patient treatment programs and in turn improve the QoL for burn survivors, as well as to provide research data to provide an even greater understanding of the biopsychosocial issues associated with sexuality and body image issues following a burn injury.

Following most forms of trauma injury, sexuality has been largely ignored within the research domain,¹⁶ thus there is an urgent need for quality, empirical research across all trauma groups, to understand the lived experiences of trauma survivors and develop effective therapeutic rehabilitation strategies. Evidence from the literature suggests that addressing the biopsychosocial aspects of sexuality within the rehabilitation setting can potentially result in the reduced need for long term interventions, such as, ongoing follow up in outpatient clinics, multi-disciplinary interventions and pharmacological management.¹⁷⁻²² Translation of research findings could therefore result in a reduction in the need for these services on an ongoing basis, which would directly result in a more cost effective use of medical resources, without compromising important aspects of trauma recovery.

Research on the surface/sensory interface of the scarring and the role of neuroplasticity on psychological and psychosocial function requires greater investigation. The findings of this research indicate that it is the physical appearance of scar tissue and the perceived reaction of others that causes the most distress in female burn survivors. As a result many female burn survivors modify their social and sexual behaviour as an adjustment and coping mechanism towards perceived negative reaction or stigmatisation of others. To date there have been no comprehensive studies that investigate general appearance and the appearance of scarring in burn survivor and non-burn survivor groups.²³ Two randomised control trials of psychosocial functioning with the use of cosmetic camouflage have been conducted in the Australian and New Zealand paediatric burn population.^{24, 25} Whilst these clinical trials have indicated that cosmetic camouflage potentially improves psychosocial functioning and QoL in children and adolescents, these studies have had significant methodological limitations that reduce the generalizability of their findings. Additionally, there have been no studies evaluating psychosocial interventions for the treatment of appearance adjustment in the adult burn population. Continued research to develop new scar management techniques to make positive changes to the appearance of scarring and improve compliance with treatment regimes, needs to be conducted. Additionally, this research should be conducted

alongside psychosocial interventions that address adjustment to burn injuries such as cognitive behavioural techniques, social skills training and non-surgical topical applications such as cosmetic camouflage.

Lastly, drawing from the mantra of leading burn researcher Winthrop Professor Fiona Wood “the quality of outcome must be worth the pain of survival”²⁶ as burn researchers this client centred focus must remain at the forefront of all of our research. Collaboration within research teams, multi-centres and burn survivors is essential if we are to achieve the ultimate goal of ‘scarless’ healing following a burn injury,²⁶ which in turn will result in significant improvements to sexuality and body image adjustment following a burn injury for all burn survivors.

8.5 Chapter References

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Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

Appendix A: Burns Specific Health Scale

BURN SPECIFIC HEALTH SCALE (BRIEF VERSION)

Please answer (circle) ALL questions based on your condition in the last 7 days. If you did not do the activity, please estimate your answer. Please return to Burns Unit physio in the enclosed envelope. Thanks

How much difficulty do you have:	Extreme	Quite a bit	Moderate	A Little Bit	None
1. Bathing independently?	0	1	2	3	4
2. Dressing by yourself?	0	1	2	3	4
3. Getting in and out of a chair?	0	1	2	3	4
4. Signing your name?	0	1	2	3	4
5. Eating with utensils?	0	1	2	3	4
6. Tying shoelaces/bows etc?	0	1	2	3	4
7. Picking up coins from a flat surface?	0	1	2	3	4
8. Unlocking a door?	0	1	2	3	4
9. Working in your old job performing your old duties?	0	1	2	3	4

To what extent does each of the following statements describe you?	Extremely	Quite a bit	Moderate	A Little Bit	Not at All
10. I am troubled by feelings of loneliness.	0	1	2	3	4
11. I often feel sad or blue.	0	1	2	3	4
12. At times, I think I have had an emotional problem.	0	1	2	3	4
13. I am not interested in doing things with my friends.	0	1	2	3	4
14. I don't enjoy visiting people.	0	1	2	3	4
15. I have no one to talk to about my problems.	0	1	2	3	4
16. I have feelings of being caught or trapped.	0	1	2	3	4
17. My injury has put me further away from my family.	0	1	2	3	4
18. I would rather be alone than with my family.	0	1	2	3	4
19. I don't like the way my family acts around me.	0	1	2	3	4

To what extent does each of the following statements describe you?	Extremely	Quite a bit	Moderate	A Little Bit	Not at All
20. My family would be better off without me.	0	1	2	3	4
21. I feel frustrated because I cannot be sexually aroused as well as I used to.	0	1	2	3	4
22. I am simply not interested in sex any more.	0	1	2	3	4
23. I no longer hug, hold or kiss.	0	1	2	3	4

24.Sometimes, I would like to forget that my appearance has changed.	0	1	2	3	4
25.I feel that my burn is unattractive to others.	0	1	2	3	4
26.My general appearance really bothers me.	0	1	2	3	4
27.The appearance of my scars bothers me.	0	1	2	3	4
28.Being out in the sun bothers me.	0	1	2	3	4
29.Hot weather bothers me.	0	1	2	3	4
30.I can't get out and do things in hot weather.	0	1	2	3	4

BURN SPECIFIC HEALTH SCALE (BRIEF VERSION)

To what extent does each of the following statements describe you?	Extremely	Quite a bit	Moderate	A Little Bit	Not at All
31.It bothers me that I can't get out in the sun.	0	1	2	3	4
32.My skin is more sensitive than before.	0	1	2	3	4
33.Taking care of my skin is a bother.	0	1	2	3	4
34.There are things that I've been told to do for my burn that I dislike doing.	0	1	2	3	4
35.I wish that I didn't have to do so many things to take care of my burn.	0	1	2	3	4
36.I have a hard time doing all the things I've been told to take care of my burn.	0	1	2	3	4
37.Taking care of my burn makes it hard to do other things that are important to me.	0	1	2	3	4
38.My burn interferes with my work.	0	1	2	3	4
39.Being burned has affected my ability to work.	0	1	2	3	4
40.My burn has caused problems with my working.	0	1	2	3	4

BURN SPECIFIC HEALTH SCALE (BRIEF VERSION)

Kildal M, Andersson G, Fugl-Meyer AR, Lannerstam K, Gerdin B 2001, 'Development of a Brief Version of the Burn Specific Health Scale (BSHS)', Journal of Trauma, Injury, Infection and Critical Care, vol 51, pp.740-746.

Appendix B: Human Research Ethics Approvals

memorandum

To	Dr Gareth Merriman, Public Health
From	A/Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval HR 196/2008
Date	08 July 2009
Copy	Kylie Black, Public Health Fiona Wood, Director of Burns Unit, Royal Perth Hospital Graduate Studies Officer, Faculty of Health Sciences

Office of Research and Development

Human Research Ethics Committee

TELEPHONE 9266 2784

FACSIMILE 9266 3793

EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled "*Quality of Life Following Trauma: An Exploratory Study of the Impact of Scarring on Sexuality and Body Image of Females who have sustained a Burn Injury*". Your application has been reviewed by the HREC and is **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 196/2008**. *Please quote this number in any future correspondence.*
- Approval of this project is for a period of twelve months **07-07-2009** to **07-07-2010**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **07-07-2010**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants:

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 196/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:

When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,

A/Professor Stephan Millett

Chair Human Research Ethics Committee



ETHICS COMMITTEE

Prof F M van Bockxmeer PhD MHGSA, ARCPA, FAHA
PathWest Laboratory Medicine
Email: Frank.VB@health.wa.gov.au

Ethics Office
Room 5105 Level, 5 Colonial House
Tel: 9224 2292; Tel: 9224 3688

Ref: EC 2009/108

(This number must be quoted on all correspondence)

29th March 2010

Kylie Black
Burns Unit
[Royal Perth Hospital](#)

Dear Kylie

EC 2009/108 Quality of life following trauma: An exploratory study of the impact of scarring on sexuality

Thank you for your responses to the queries raised by the Ethics Committee and I am pleased to advise that the above study is now **APPROVED**.

The following general conditions apply to all approvals by this Committee, and starting a trial or research project following the issue of ethics approval will be deemed to be an acceptance of them by all investigators:

1. The submission of an application for Ethics Committee approval will be deemed to indicate that the investigator and any sponsor recognises the Committee as a registered (with AHEC) Health Research Ethics Committee and that it complies in all respects with the National Statement on Ethical Conduct Research Involving Humans and all other national and international ethical requirements. **The Committee will not enter into further correspondence on this point.**
2. All income arising from the study must be lodged in a hospital special purposes account. Performance of a clinical trial for a sponsor is a service for tax purposes and all GST obligations must be met.
3. The investigator will report adverse events accompanied by a statement as to whether or not the trial should continue. The Committee reserves the right to not receive reports whose complexity or level of detail requires the expenditure of unreasonable time and effort. The Committee receives voluminous paperwork relating to adverse event reporting. From time to time the Committee chairman may require these reports to be summarised and approval is granted subject to the agreement of the investigator that he or she will prepare such a summary on request.
4. The Committee has decided that, as the responsibility for the conduct of trials lies with the investigator, all correspondence should be signed by the investigator.
5. All trial drugs must be dispensed by the Pharmacy Department. A fee is levied for this service and investigators must regard this fee as an item requiring a budget allocation. Alternatively, if a sponsor agrees, separate direct funding of pharmacy services may be undertaken. There are provisions for this fee to be waived for locally-inspired unfunded studies not having an external sponsor.
6. Though state institutions are outside the jurisdiction of the Privacy Act and related legislation, the Committee will assume that the privacy provisions of that Act will be the minimum standards applying during the conduct of a trial at Royal Perth Hospital. Traditional standards of patient confidentiality will apply.

7. The Committee will not acknowledge trial communications as a matter of course, unless they relate to a matter requiring Committee approval. Evidence of dispatch of a letter will be deemed to be evidence of receipt. This rule may be waived at the Committee's discretion on provision of a *pro forma* receipt by the investigator for the Chairman's signature and return. However, trivial correspondence (as judged by the Committee) will not be acknowledged even if a *pro forma* receipt is provided. Where an investigator requests written approval or written record of a matter for special purposes (say at the request of a sponsor), the investigator should prepare the required letter for the chairman's signature rather than expect the Committee secretary to prepare it. This mechanism increases the probability that the trial details in the letter are correct.
8. The Committee will provide the names and representative affiliation of members on request, but will not provide personal details or voting records.
9. A brief annual report on each project approved will be required at the end of each fiscal year, in default of which approval for the study may be suspended. Ethics approvals at RPH do not carry an expiry date so the annual report is an important part of Ethics Committee procedure.
10. The Committee has the authority to audit the conduct of any trial without notice. Exercise of this authority will only be considered if there are grounds to believe that some irregularity has occurred or if a complaint is received from a third party, or the Committee wishes to undertake an audit for QA purposes.
11. Complaints relating to the conduct of a clinical trial should be directed to the Chairman and will be promptly investigated. Complaints about the Ethics Committee decisions or policies that cannot be resolved by discussion with the Chairman or about any actions of a particular member including the Chairman, should be directed to the Director of Clinical Services. Only written complaints (not e-mail) will be accepted for investigation.

Investigators of sponsored studies are advised to draw the above conditions to the attention of the sponsor. Investigators are reminded that records of consent or authorisation for participation in special studies (including clinical trials) form part of the Acute Hospital Patient Record and should be stored with that record in accordance with the WA *Health Patient Information Retention and Disposal Schedule (Version 2) 2000*. A copy of the 'Patient Information Sheet' should also be included in the medical records as part of informed consent documentation.

Yours sincerely



Prof Frank M van Bockxmeer
Chairman, Royal Perth Hospital Ethics Committee

The Royal Perth Hospital Ethics Committee is constituted and operates in accordance with NH&MRC Guidelines.

Copy: Danny Koh (Business Manager)

Appendix C: Patient Information Sheet



Title of Project:

Quality of Life Following Trauma: An Exploratory Study of the Impact of Scarring on Sexuality.

Principle Researcher:

Kylie Black, BOT, Post Grad For. Sexology

Registered Occupational Therapist

Telstra Burns Outcome Centre

Royal Perth Hospital

Telephone: (08) 9224 2244

Purpose of the study:

The purpose of this study is to explore the extent to which trauma impacts sexuality, body image and relationships with people who have sustained a physical trauma through injury. The aim of the study is to determine whether issues of a sexual nature are being addressed within the rehabilitation setting and provide a framework for improvements based upon identified need and recommendations from both patients and staff attending outpatient rehabilitation services.

Your role in the study:

If you enter this study, you will receive be asked to complete a series of questionnaires relating to your thoughts and feelings regarding sexuality, body image and relationships. You may also be invited to participate in a focus group discussion that is aimed at discussing the above issues in more depth.

Participation in this study will involve completing a series of questionnaires that will take about 15 mins. These questionnaires can be completed during one of your

scheduled outpatient appointments. Should you be interested in participating in a focus group discussion you will be contacted by the principle researcher to arrange a convenient time for you to attend a group discussion as these will be conducted at a later time when there is enough participants to run a group. These focus group sessions will run for no longer than 1 hour.

Risks and Benefits

Enrolment into this study will not affect your access to your full range of outpatient services.

As this study is based on exploring the inclusion of sexuality within rehabilitation programmes some questions will be based upon your thoughts and feelings regarding your sexuality, perceptions of your body appearance and issues regarding your personal relationships following your injury. You will not be asked any questions regarding specific sexual practices/activities. Questions therefore should be of little or no discomfort however questions should bring forth any issues that you would like to speak to a health professional about you are encouraged to contact the RPH Telstra Burns Outpatient Clinic on 92242154 or speak directly with the researcher who will arrange a referral to an appropriate health professional for you.

Confidentiality

All participants who enter this study will be allocated with a patient number. No identifying details will appear on any of the data. The researcher will hold any information gathered in the strictest confidence.

The data will be stored in two ways. Firstly data gathered will be entered into a computer at the Royal Perth Hospital that has a programme specifically designed to analyse statistical data. No identifying details will be entered in to this computer and only the researcher can access the data gathered via a password known only by the researcher. Secondly all hard data will be stored in a locked filing cabinet. The data will be stored for a period of seven years as required by law.

The researcher will comply with all standards of privacy as set out by the Australian Privacy Act 1988. The researcher has outlined assurances to the Ethic Committee that the 'Information Privacy Principles' outlined in the act will be adhered to at all times.

It is intended that the results of this research will be published in overseas journals. At no times will individuals be able to be identified in any publications resulting from this study.

Refusal or withdrawal

Enrolment into this study is purely voluntary and as such you may refuse to participate at any stage. Should withdrawal at any point your decision will be respected without prejudice to your medical, Nursing or Allied Health care. If you decide to withdrawal from this study please contact the principle researcher as soon as possible and she will ensure your data is destroyed.

Requests for more information

The Ethics Committee at Royal Perth Hospital and Curtin University of Technology have approved this research project. If you require any further information this may be obtained from the Principle Researcher at the number provided, from Assoc Prof F M Van Brockxmeer, Chairman of the Ethics Committee, telephone (08) 9224 2244, or from Curtin University of Technology Human Research Ethics Committee, Office of Research & Development, Curtin University of Technology, GPO Box U1987, PERTH WA 6845.

Requests for copies of any journal publications that result from this study may be requested from the principle researcher.

Thank you for your participation in this study

Appendix D: Patient Consent Form



Patient Consent Sheet

Title of Project:

Quality of Life Following Trauma: An Exploratory Study of the Impact of Scarring on Sexuality

Principle Researcher:

Kylie Connell, BOT, Post Grad For. Sexology
Registered Occupational Therapist
Telstra Burns Outcome Centre
Royal Perth Hospital
Telephone: (08) 9224 2244

I,..... Agree to participate in the above study. I have received and read the Study Information Sheet and have had the opportunity to ask any questions about the study. I am over the age of 16 yrs and understand that participation in this study is voluntary and as such I am able to withdrawal at any stage. I understand that withdrawal from this study will not affect any future medical treatment. I give my permission for any results to be used in any report, research or conference paper, for the purposes of this study and subsequent studies conducted by the researcher, with the understanding that my identity will be kept confidential.

I understand the researcher will adhere to professional standards of confidentiality in respect to the collection, handling and storage of my personal data and that these standards meet the conditions of the Privacy Act 1988.

Signed..... Date.....

(Patient)

I have explained the nature and purpose of this study. The procedures involved in this study have been outlined including the collection, handling, storage and publication of data obtained. The subject has consented to this study voluntarily and I have answered all questions that have arisen.

Signature of Researcher Date.....

Appendix E – Copyright Permissions for the Reproduction of the Following Article for the Purposes of this Thesis:

Connell, K.M., Coates, R., Wood, F.M. (2014). Sexuality Following Trauma Injury:
A Literature Review. *Burns & Trauma*, 2(2), 62-70.

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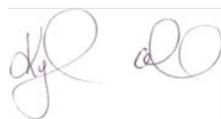
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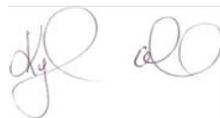
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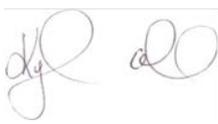
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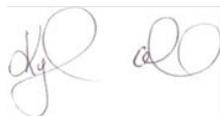
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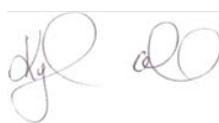
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