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Sexual Role Functioning, Sexual Satisfaction, and Intimacy after Surviving
Burn Injuries: A Scoping Review of Associated Factors, Screening Tools,
and Burn Care Staff Preparedness.

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Abstract

Although concerns regarding intimacy abound among burn survivors, these are often not captured during rehabilitation. Considering that sexuality remains a part of humans suggests a critical need to pay attention to this aspect. To guide further work, this review sought to examine existing studies to ascertain what is known about factors associated with sexual role functioning, sexual satisfaction, and intimacy, the screening tools employed, and the preparedness of burn care staff in initiating discussions about these. We employed a scoping review approach with extensive searches in four peer-reviewed databases for studies reporting on the phenomenon, published in English from 2010 to date. Seventeen studies comprising of thirteen studies reporting on the burn survivors and four reporting on burn care staff were retained. Though we identified both sociodemographic and clinical factors associated with post-burn sexual role functioning, sexual satisfaction, and intimacy, the existing evidence appear limited which made it rather difficult to draw definitive conclusions. The sexuality subscale of the Burn Specific Health Scale- Brief emerged as the commonly used screening/ assessment tool. The evidence suggest that burn care staff are generally unprepared to initiate discussions regarding sexual role functioning, sexual satisfaction, and intimacy and often, there is no personnel assigned to this task. There is a great need for studies to strengthen the evidence base regarding the factors associated with post-burn sexual role functioning, sexual satisfaction, and intimacy. Additionally, it is imperative to build capacity of burn care practitioners with the requisite know-how needed to navigate through sexual issues.

Keywords: Burns; Intimacy; Provider preparedness; Sexual role functioning; Sexual satisfaction; Screening

Introduction

Burn care has advanced over the years to improve survival outcomes albeit with emerging long-term psychosocial issues related to the protracted nature of the post-burn sequelae [1]. Several studies have highlighted that persons who survive burns often experience varying degrees of social challenges and may experience challenges in participating in leisure and other social activities [2, 3]. Participating in social activities such as those related to leisure, work, school, romantic relationships/intimacy, and sexuality can often be challenging for burn survivors due to the nature of the post-burn sequelae such as scars which can have a noticeable look, evoke intrusive questioning, and lead to stigma [4]. Besides, post-burn scars can lead to an altered sense of body image which can adversely impact on an individual's ability to enjoy leisure, work, and school activities [4, 5].

Although existing post-burn rehabilitation programmes seek to support return to work, school, and other leisure activities, the aspects of intimacy and sexual role functioning often seem neglected [6]. Engaging in romantic relationships/ intimacy and sexual role functioning are key aspects of what it means to be a social being and are essential components of the experiences of humans [7]. For burn survivors, there are often concerns regarding intimacy, decreased libido, and role performance anxiety/ fear [8, 9]. In a recent study that sought to illuminate the nature of post-burn rehabilitation programmes, the authors identified varied components in biopsychosocial domains, albeit no component targeting romantic relationships/ intimacy and sexual role functioning were identified which may suggest the limited attention paid to this critical aspect of the post-burn recovery process of adult burn survivors [6].

Undoubtedly, issues relating to sex and intimacy are shrouded in secrecy and euphemisms in several parts of the world. Burn care staff may feel extremely uncomfortable discussing issues relating to sexuality and intimacy openly with their patients. Burn patients and their significant others, on the other hand, may also feel shy, uncomfortable, or embarrassed to ask their care providers questions regarding intimacy and sexual role functioning after surviving the injury. Consequently, the extent to which burn survivors engage in romantic relationships/ intimacy, concerns regarding sexual role functioning, intimacy, and sexual satisfaction remain poorly

articulated. What is more worrying is the fact that there is a general lack of interventions, post-burn sexual health educational materials, and resources in these areas for burn care practitioners, burn patients, and their families [10]. Even though the World Health Organisation acknowledges that sexual health is relevant throughout a person's life [11], there is a general lack of guidelines to support burn care staff in navigating through this aspect of care following burn injury survival.

In other illness contexts such as spinal cord and traumatic brain injuries, there has been significant efforts to uncover issues relating to sexuality, intimacy, and reproductive health [12, 13]. These have guided the development of interventions to support affected persons and their significant others. Within the burn patient/ survivor population, a correlation has been observed between greater burned surface area, altered body image following the injury, and lower sexual satisfaction with gender variations across the experience of sexual intimacy (male burn survivors more likely to talk openly about sexuality compared to women) [14-16]. Interestingly, some studies have observed that increasing burned surface area may be related with declines bodily appearance/ image, but not intimacy or sexual satisfaction, sexual role functioning, or intimacy [17, 18]. Put together, the findings may suggest a need for more studies to articulate the factors associated with intimacy, sexual role performance, and sexual satisfaction after burns. Additionally, it is critical to examine how prepared burn care staff are to initiate discussions around sexual intimacy as a part of post-burn rehabilitative care to offer support to further work in this regard. In response to the identified gaps, we sought to review and synthesis existing studies to ascertain what is known about the factors associated with post-burn sexual role functioning, intimacy, and sexual satisfaction. The secondary objectives include ascertaining the tools employed by existing studies to screen post-burn sexual role functioning, intimacy, and sexual satisfaction/ dissatisfaction and burn care staff preparedness in supporting burn survivors in this regard.

Materials and methods

Design

We employed Arksey and O'Malley [19] approach to scoping review and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension guidelines for scoping reviews in reporting this review [20]. A

protocol was formulated for this review albeit it was not published but served as a guide for the conduct of the main review. The protocol contained the search strategy, information sources to be searched, and eligibility criteria that guided this study. The protocol was flexible and adapted to suit each information source. Though the protocol was not published, it is available on request.

Information sources, search strategy, and eligibility criteria

The following electronic databases were searched for peer-reviewed studies regarding intimacy and sexual role functioning in the burn patient population: EMBASE via Ovid, Web of Science, CINAHL via EBSCHO, and PubMed. The bibliographic lists of identified studies were also hand searched for potential papers. Considering the scoping nature of the study, the research team also searched ProQuest Dissertations and the Theses Global Database, Trove, MedNar, OpenGrey, and the Agency for Healthcare Research and Quality were searched for potential thesis and grey literature reporting on the phenomenon. The search terms used include: 'burns' OR 'burn' AND 'intimate relationships' OR 'romantic relationships' AND 'sex' OR 'sexuality' OR 'sexual' OR 'sexual satisfaction' OR 'sexual dissatisfaction' OR 'sexual health' AND 'adult burn survivor'. The eligibility criteria were studies exploring intimacy, romantic relationships, sex, sexual satisfaction, and sexual role functioning in adult burn survivors regardless of the study design and published in English. Considering previous work in this area, we limited the search to only studies published from 2010 to date. To scope the literature extensively, case reports focusing on the phenomenon under investigation were considered potentially eligible for this study. This notwithstanding, the following were considered ineligible as they were deemed not to offer much information required and as such excluded: abstracts from conferences, preprints, letters to the editor, and editorials Also, non-English studies were excluded. The processes of searching and retention are reported in a PRISMA flowchart presented as Figure 1.

Selection of sources of evidence

Following extensive searches across all the databases, the identified studies were pooled to EndNote X9.2 [21] after which duplicates were removed and exported to the Rayyan software [22]. Two authors concurrently reviewed the titles and abstracts to identify potential studies that met the criteria for inclusion. All excluded studies were pooled to another folder in Rayyan [22]. Full-text versions of the eligible

studies were then outsourced from the databases and reviewed to ensure they met the criteria for inclusion. At the end of the screening process, seventeen (17) studies remained and were included in the study.

Data charting process and synthesis

Data extracted from the retained studies include authors, year, setting, study aim, participants, key findings relating sexual role functioning, sexual satisfaction, and intimacy, and the study conclusions (see table 1). To synthesise the data, the studies were firstly segregated into those reporting on the burn survivors and those that focused on the burn care practitioners. The authors extracted and formulated codes regarding sexual role functioning, sexual satisfaction, and intimacy of burn survivors and burn care practitioners' preparedness using a constant comparative analytical approach. The constant comparative analytical approach involved the sorting and organization of data in a structured way according to their attributes [23]. The extracted codes were reviewed by two authors independently, and similar codes were aggregated to formulate categories. The independent codes and categories were reviewed by other team members to ensure rigor. In case of discrepancies/ disagreements, we employed team discussion to achieve consensus. Following team consensus on the codes and categories, the categories were reviewed and aligned with the study aim to formulate concepts, that is, screening tools, factors associated with sexual role functioning, sexual satisfaction, and intimacy, and provider preparedness. The concepts and categories formed the basis of undertaking a narrative synthesis.

Collating, summarizing, and reporting the results Study characteristics

Seventeen studies comprising of fifteen primary studies, and two reviews were retained in this study (see table 1). Thirteen studies focused solely on burn survivors (two studies on male and two studies on female burn survivors), and four studies reported on burn care staff [10, 24-26]. Majority of the studies (n=5) emerged from the United States [10, 18, 27-29], three studies from Australia [9, 14, 15], and one study each from Brazil [25], Canada [26], India [30], Iran [31], Sweden [32], Turkey [33], and the United Kingdom [24]. The primary studies reporting on the burn

survivors focused on varying post-burn periods including 3 to 6 months [33], 6 months to 1 year [18], 1 to 12 months [15], and 6 months to 7 years post-burn [32].

Screening tools for sexual role functioning, sexual satisfaction, and intimacy

Screening/ assessment tools identified across the retained studies include sexuality subscale of the Burn Specific Health Scale- Brief to examine issues/ concerns relating to sexual and intimacy [14, 15, 32]; sexuality scale component of the Maudsley Marital Questionnaire to examine sexuality satisfaction [30], the International Index of ED-5 (IIEF-5) to examine alterations in erectile functions after major burns [33], the Index of Sexual Satisfaction (ISS) [31], Sexual Relationships, Social Interactions, and Romantic Relationships components of the Life Impact Burn Recovery Evaluation (LIBRE) profile [28, 29], and sexual satisfaction scores using the Burn Model System (BMS) National Database [18]

The Burn Specific Health Scale-Brief employed by the three studies [14, 15, 32] is a 40-item instrument with nine subscales (simple abilities, hand function, heat sensitivity, treatment regimens, body image, affect, interpersonal relationships, sexuality, and work). Responses to the items are made on a five-point scale ranging from 0 (all the time/great difficulty) to 4 (never/no difficulty) with higher scores demonstrating better perceived health status and vice versa. Cronbach alphas for the subscales are high ranging from 0.79–0.85 [14, 15, 32]. The Maudsley Marital Questionnaire employed by Ahmad et al. [30] comprises of 20 items with 5 questions targeting sexual satisfaction on a scale of 0-8. The sexuality subscale has a Cronbach's alpha of 0.80 and higher scores on the scale are indicative of adjustment problems. The IIEF-5 employed by Aknediz et al. [33] comprises of five questions on a scale from 1-5 with Cronbach's alpha of 0.94 and higher scores demonstrate the absence of erectile dysfunction. The Index of Sexual Satisfaction (ISS) used by Kazamzadeh et al. [31] comprises of 25 items and a Cronbach's alpha of 0.92 with greater scores demonstrating greater sexual dissatisfaction. The LIBRE profile employed by Levi et al. [28] and Ohrtman et al. [29] comprises of 126 questions with 28 and 15 items targeting romantic (intimate) and sexual relationships respectively with repeatability coefficients ranging from 7.31 to 9.27. The BMS model employed by Cato et al. [18] is a burn injury repository in the United States.

Factors associated with sexual role functioning, sexual satisfaction, and intimacy after burns

Two categories of findings were identified to be associated with post-burn sexual role functioning, sexual satisfaction and intimacy: 1) sociodemographic factors, and 2) clinical factors.

1. Sociodemographic factors

Age: Pandya, Corkill, and Goutos [34] reported in their literature review that age at the time of the injury could affect the quality of a burn survivor's sexual life. Goncalves et al. [35] highlighted in their integrative review that sexual dysfunction following burn injury could be related to a younger age group. Conversely, Connell et al. [15] observed a negative association between age and the sexuality sub-scale of the BSHS-B from 1 month to 12 months post-burn which implied that the older the patient, the greater the likelihood that the burn patient/ survivor may report some level of impact on the BSHS-B sexuality-specific items. At 24 months, Connell et al. [14] observed that men scored lower on the sexuality subscale of the BSHS-B with increasing age whereas women scored higher on the same scale with increasing age. Cato et al. [18] highlighted increasing age as a notable sociodemographic factor associated with lower sexual satisfaction up to 5 years post-burn based on the Burn Model System National Database. Between 24 months to 7 years post-burn, Oster and Sveen [32] observed in their longitudinal study involving Swedish burn survivors that age was not significantly associated with sexuality scores (based on the BSHS-B) in their bivariate regression models.

Gender: Some studies included in this review highlighted gender variations in post-burn sexual role functioning, intimacy, sexual satisfaction. One qualitative study that included five female burn survivors observed that the injuries often led to behavioral changes that have a potential adverse impact on sexual and social engagement for female burn survivors [9]. In an earlier with both male and female burn survivors, Connell et al. [15] identified a negative association between gender and the body image sub-scale of the BSHS-B which implied that females were more likely to have greater impact scores than males. The authors noted that sexual arousal difficulties affected both males and females similarly, particularly at 6 and 12 months [15]. Despite this similarity, the authors noted that more females expressed a loss of sexual

interest and concerns regarding changes in hugging, holding hands, and kissing at 12 months post-burn. In contrast, however, they noticed that men struggled with these components at the initial stages of rehabilitation.

In another study that focused solely on female burn survivors, the authors reported that majority of the participants (82%) with severe burns had lower levels of sexual satisfaction which was associated with altered appearance or body image [31]. Levi et al. [28] also reported that men scored significantly better than women on sexual relationships, social interactions, work & employment, and romantic (intimate) relationships of the LIBRE profile scales. Using the same profile, Ohrtman et al. [29] also noted that men were likely to report being in a sexual relationship following the burn injury.

Although Ahmad et al. [30] reported that more males (n=218) than females (n=70) experienced sexual dissatisfaction at 6 months post-burn using the Maudsley Marital Questionnaire (sexual sub-scale only), Oster & Sveen [32] observed difference in the mean scores of the sexuality subscale of the BSHS-B between men and women at 6 to 24 months after the burn; with women reporting less satisfaction compared to men. From 2 to 7 years follow-up, the authors noted a statistically significant increase in mean scores among men when compared to female burn survivors [32]. Despite the observed variations, men with genital burns often suffer long-term urinary and/ or sexual (or erectile) dysfunction which can evoke feelings of frustration and anxiety associated with sexual role performance [27, 33, 35].

Marital status and living arrangement: Being single or divorced was reportedly associated with lower sexual satisfaction regardless of gender [18]. Additionally, Oster and Sveen [32] observed that not living alone at the time of the injury was associated with higher scores on the sexuality subscale albeit only significant at 12 and 24 months. **Employment status**: Burn survivors who are not working were observed to be less likely to be sexually active or in a romantic (intimate) relationship [29].

2. Clinical factors

Burn injury characteristics and post-burn sequelae: This section examines the impact of various injury characteristics and its aftermath on sexual role functioning, sexual satisfaction, and intimacy. Injury characteristics such as total burn surface area (TBSA), burn depth, site of burn, and post-burn scars were identified as potential

factors associated with sexual role functioning and intimacy albeit mixed. Majority of the sexually dissatisfied persons (n=288) in the study by Ahmad et al. [30] had a TBSA ranging from 30% to 40% and of second-degree category as at the time of admission. Aknediz et al. [33] also reported long-term altered erectile dysfunction at 6 months following a major burn among males. In similar lines, severe burns were reported to be associated with lower sexual satisfaction among female burn survivors [31]. Connell et al. [15] also reported a negative association between TBSA and the body image sub-scale of the BSHS-B indicating that the higher the TBSA, the greater the likelihood of reporting some level of impact following burn injury survival. Potentially, altered body image may also impact sexual role functioning, sexual satisfaction, and intimacy as described in the next paragraph.

The two reviews included in this current study also underscored the potential impact of TBSA and burn depth on body image which can impact sexual role functioning and intimacy following burn injury survival [34, 35]. These are congruent with the findings by Oster and Sveen [32] as they noted that increasing TBSA and burn depth were associated with lower scores on the sexuality subscale of the BSHS-B at 6 months, 12 months and 2–7-year follow-up, but not at 24 months. Also, burns to the genitalia often led to visible scarring which led to limited or non-participation in any sexual activity due to fear of rejection, anxiety, and frustration [27, 35]. Burn survivors with burns to the hands were also observed to be more likely to report being sexually active and in a romantic/ intimate relationship albeit in an adjusted model (based on age, male gender, race, education, and working status), time since burn injury, burn size, and burns to critical areas such as the face, genitals, and hands were not significantly associated with sexual activity or romantic (intimate) relationship outcomes [29]. One study did not identify any association between injury characteristics such as TBSA and burn depth and sexual role functioning and intimacy [18].

Length of stay/ hospitalisation: This section presents the review findings regarding the impact of length of hospital stay/ hospitalisation on sexual satisfaction, sexual role functioning, and intimacy. Ahmad et al. [30] reported statistically significant associations regarding duration of hospital stay and either sexual satisfaction or dissatisfaction. The authors noted that burn patients admitted for <15

days were a significant subgroup or sexually satisfied cases whereas patients admitted for >60 days were sexually dissatisfied cases and the most common concerns in the latter group included loss of libido, humiliation in showing the burned area, pain at the injured site, fatigue, fear of disappointing the partner, dyspareunia, and vague reasons. Goncalves et al. [35] also noted in their integrative review that prolonged hospitalisation can adversely the post-burn sexual experience. Further to these, Oster and Sveen [32] highlighted that more severe burns that required longer length of hospitalisation was associated with lower score on the sexuality subscale of the BSHS-B at 6 months, 12 months, 2 years, and 7 years post-burn, but not at 24 months post-burn. Put together, longer periods of hospitalisation are potentially associated with sexual dissatisfaction and lower scores on sexual role functioning.

Psychiatric morbidity and coping strategies: A history of psychiatric morbidity was observed to be associated with lower scores on the sexuality subscale of the BSHS-B from 6 months to 7 years post-burn, but not at 24 months [32]. Higher levels of the personality trait neuroticism were highlighted by the authors to be associated with lower scores on sexuality at each time point [32].

Further to the above, aggressiveness and sensation seeking were not associated with sexuality, with the exception that there was a correlation between sensation seeking and sexuality at 6 months [32]. Two review studies underscored that the use of avoidance coping mechanisms was associated with worsened sexuality [34, 35].

Burn Care Staff Preparedness in initiating discussions about intimacy

Four studies evaluated burn care staff preparedness in discussing post-burn sexuality issues and management strategies. These studies emerged from the United Kingdom [24], Brazil [25], Canada [26], and United States [10]. All four studies employed a cross-sectional approach with burn care staff. The sample sizes in these studies were 124 [25], 71 [10], 56 [24], and 32 burn care practitioners [26].

The study by Rimmer et al. [10] was identified as the first extensive survey to examine the practices regarding discussing sexuality and intimacy issues among burn care staff. In this study, a 28-item survey, designed by seasoned burn care professionals and survivors was used. The authors noted that the questionnaire was tested for clarity by six additional burn care professionals, including two burn surgeons,

three burn nurses, and a burn psychologist, before distribution. Additionally, Cronbach's alpha was assessed as 0.87, indicating a high degree of reliability. Piccolo et al. [25] used the same questionnaire in their study that investigated how Brazilian burn care staff navigated sexuality issues after burns. Pignanelli et al. [26] used a modified version of the questionnaire with 24 items instead of the original 28 items to examine current practice, patterns, views, and beliefs on sexual function by 32 burn care staff in Canada using a survey approach. Hurley et al. [24] reported using a selfdeveloped set of nine questions to ascertain opinions regarding management strategies of post-burn sexuality and intimacy issues among UK burn care practitioners. The 9-item tool employed by Hurley et al. [24] reflected four different topics including importance of the post-burn sexuality topic, how often the topic was discussed, who the responsibility lies with to discuss the topic and access to education surrounding the topic. Each question was stand alone with a different set of answers for each question and elicited categorical, multiple choice and free text answers. Despite the extensive development phase, the psychometric properties of the 9-item tool were not reported.

Though burn care staff across all the four studies underscored the importance of sexual function and intimacy after burn injury, it often remains unaddressed. Rimmer et al. [10] observed that though majority of the participants (95%) agreed that the patient should not have the responsibility of asking questions relating to sexuality after burns, up to 55% of the study participants were only likely to discuss sexuality and intimacy if the patient/partner initiated the discussion. It was noted that designated staff to offer education was generally lacking with limited comfort on the part of the burn care staff to initiate such discussions. The absence of a designated burn care staff to handle or be responsible for discussions relating to sexual intimacy after burns was also resonated in the study by Pignanelli et al. [26] with burn care staff often not addressing these issues. Similarly, majority of burn care staff in the study by Hurley et al. [24] reported that they never or only occasionally ask burn patients about their sexual function concerns with the authors highlighting the absence of a designated burn care staff to lead care in this area. Participants in the study by Piccolo et al. [25] reported that discussions around sexuality and intimacy following burns should be done by a psychologist although few burn care staff (n=35,

28%) noted feeling comfortable in initiating conversation about sexual intimacy with burn survivors. Considering these findings, it is possible to deduce that no burn care staff may not be prepared to handle issues relating to sexual role functioning and intimacy following burns, and such discussions are often left to chance rather than the availability of a structured approach to initiating such discussions and offering support where available.

Discussion

The study sought to map the existing evidence to ascertain what is known about sexual role functioning and intimacy following burns with focus on associated factors, screening tools, and burn care staff preparedness in initiating discussions around these. The review findings highlight a variety of factors potentially associated with sexual role functioning, sexual satisfaction, and intimacy following burns albeit the existing evidence appear either small or mixed and makes it difficult to draw strong conclusions regarding these factors. The mixed findings or limited evidence notwithstanding, the findings suggest variations in sexual intimacy may improve over time following the injury. Also, the current review findings underscore that burn care staff are not prepared to initiate discussions in this regard and in most instances, there is no specific practitioner assigned to support burn patients/ survivors and their families in navigating this aspect of the post-burn recovery process. Put together, there is a critical need for more studies to strengthen the evidence base regarding associated factors more in-depth using national burn repositories and across countries which can inform practice. Additionally, there is a great need to equip burn care staff with the requisite skills, knowledge, and confidence to support burn survivors and their families in navigating this sensitive aspect of the post-burn recovery process.

In the current study, we identified both sociodemographic and clinical characteristics that may be associated with sexual role functioning, sexual satisfaction, and intimacy following burn injury survival. Though the evidence seems either small or mixed, it may offer insight into potential groups of persons who may benefit from early screening and support. The evidence so far suggests that sociodemographic characteristics (increasing age, female gender, living alone/ divorced, and being unemployed), and clinical factors (injury characteristics, length of stay, and underlying psychiatric morbidity) may be associated with sexual intimacy issues and lower sexual

satisfaction albeit these may not be a one-size-fit-all considering the heterogenous nature of the burn patient/ survivor population and the changes that occur over time. Besides, the presence of one factor may not necessarily imply existing challenges with sexual role functioning and intimacy considering the varied coping mechanisms across individual burn patients/ survivors. Instead, just as an individualised approach to post-burn rehabilitation is highly recommended, an individualised, comprehensive approach to evaluating sexual intimacy issues should be considered to inform professional support and underpin a patient/ family-centred approach to post-burn sexual rehabilitative care.

Two previous reviews that examined sexuality following burns noted that younger age and increasing TBSA were potentially associated with post-burn sexual dysfunction [34, 35]. Conversely, some evidence included in the current review either did not ascertain any significant association between these variables [32] or increasing age to be associated with greater impact on sexuality [15, 18]. A thesis identified during our extensive search which focused on burn survivors (n=117) in Belgium and the Netherlands also observed that TBSA was associated with decline in body image, but not sexuality [17]. Undoubtedly, greater TBSA may suggest greater damage to the body which can lead to extensive scarring and adversely impact the sense of an altered body image. However, some burn survivors can experience post-traumatic growth, accept, and learn to live satisfactory lives with the altered selves [18]. Besides, the notion of sexual intimacy as a subjective and multidimensional construct may vary across ages and the mixed findings may affirm a great need for more studies to examine the link between the variables.

The sexuality sub-scale of the BSHS-B emerged as a common assessment/ screening tool. The BSHS-B is a valid and reliable tool used on assessing burn-specific quality of life with nine domains. Each domain is internally consistent and can be used as separate clinically meaningful sub-scale to evaluate post-burn patients. The sexuality subscale comprises of three questions which may offer insight into areas of potential concern. Findings from such screening can guide further action or in-depth exploration.

The World Health Organization and Healthy People 2020 emphasise the importance of sexual healthcare for all patients [36]. The post-burn recovery process

can often be protracted with varied issues emerging. Though rehabilitation programmes exist to support burn survivors, sexual role functioning and intimacy issues often remain poorly attended to. In this study, we uncovered the lack of preparedness among burn care staff in initiating sexual intimacy discussions and in most instances, there is no designated practitioner responsible to handle this aspect of the post-burn recovery process. Although most participants in one Brazilian study highlighted that sexual intimacy issues should be handled by a psychologist [25], it may be essential to equip the members of the multidisciplinary burn care team with basic skills to initiate such discussions and refer more complex issues to the psychologist. This is particularly essential as sexual intimacy topics are often not included in the curriculum of training healthcare practitioners and remain shrouded in secrecy [37]. Another consideration that can potentially improve the situation will be to develop post-burn sexual rehabilitation guidelines to support burn care practitioners in navigating through these issues following the injury. This is important as existing professional burn care organisations such as the American Burns Association, British Burns Association, European Burns Association, and International Society for Burn Injuries currently do not have guidelines regarding how to address post-burn sexuality and intimacy issues. Additionally, patient education resources such as booklets and charts should be developed and used to ease access to intimate issues following burn injury survival.

A notable strength of this review is the inclusion of studies regarding both burn care practitioners and burn survivors which can offer transferability to burn care practice. Despite the interesting findings uncovered in this study, some limitations are noteworthy. Firstly, only studies published in English were considered for inclusion which may have led to excluding other relevant non-English studies. Secondly, most of the studies included in this review are limited by small sample sizes and usually employed descriptive, correlational approaches. The limited number of qualitative studies identified in this area also makes it difficult to articulate the sexual intimacy experiences of burn survivors more fully.

Conclusion

Sexual intimacy remains a key aspect of what it means to be a person and for burn survivors, several factors come to play regarding how sexually satisfied or dissatisfied they may be. Although the existing evidence regarding the factors associated with post-burn sexual intimacy experience seems either limited or inconclusive, it is evident that several changes may occur over time making it even more cogent to include this aspect in post-burn rehabilitation programmes. Burn care staff are generally unprepared to initiate discussions about sexual intimacy which can be a significant barrier. Thus, there is a critical need to equip burn care staff with skills to enable them support burn survivors in this regard.

References

- [1] Kumar, R., Keshamma, E., Kumari, B., et al., (2022). Burn Injury Management, Pathophysiology and Its Future Prospectives. *Journal for Research in Applied Sciences and Biotechnology*, *1*(4), 78-89.
- [2] Druery M, Newcombe PA, Cameron CM., et al., Factors influencing psychological, social and health outcomes after major burn injuries in adults: cohort study protocol. *BMJ Open* 2017;7:e017545, doi: 10.1136/bmjopen-2017-017545.
- [3] Ohrtman EA, Shapiro GD, Simko LC, Dore E, Slavin MD, Saret C, et al. Social interactions and social activities after burn injury: a life impact burn recovery evaluation (LIBRE) study. *J Burn Care Res* 2018;39:1022–8, doi: 10.1093/jbcr/iry038. [4] Bayuo, J., Wong, F. K. Y., Lin, et al., (2023). A meta-ethnography of developing
- and living with post-burn scars. *Journal of Nursing Scholarship*, *55*(1), 319-328.
- [5] Brewin, M. P., & Homer, S. J. (2018). The lived experience and quality of life with burn scarring—the results from a large-scale online survey. *Burns*, *44*(7), 1801-1810.
- [6] Bayuo, J., & Wong, F. K. Y. (2021). Intervention content and outcomes of postdischarge rehabilitation programs for adults surviving major burns: a systematic scoping review. *Journal of Burn Care & Research*, *42*(4), 651-710.
- [7] Bond, K. T., & Radix, A. E. (2024). Sexual Health and Well-Being: A Framework to Guide Care. *Medical Clinics*.
- [8] Bayuo, J., Wong, F. K. Y., & Agyei, F. B. (2020). "On the Recovery Journey:" An integrative review of the needs of burn patients from immediate pre-discharge to post-discharge period using the Omaha System. *Journal of nursing scholarship*, *52*(4), 360-368.

- [9] Connell, K. M., Coates, R., & Wood, F. M. (2015). Burn injuries lead to behavioral changes that impact engagement in sexual and social activities in females. *Sexuality and Disability*, *33*, 75-91.
- [10] Rimmer RB, Rutter CE, Lessard CR, Pressman MS, Jost JC, Bosch J, et al. Burn care professionals' attitudes and practices regarding discussions of sexuality and intimacy with adult burn survivors. *J Burn Care Res* 2010;31:579–89, doi: 10.1097/BCR.0b013e3181e4d66a.
- [11] World Health Organization. Developing sexual health programmes: A framework for action. World Health Organization; 2010.
- [12] Kreutzer JS, Marwitz JH, Hsu N, Williams K, Riddick A. Marital stability after brain injury: An investigation and analysis. NeuroRehabilitation. 2007 Jan 1;22(1):53-9.
- [13] Zizzo J, Gater DR, Hough S, Ibrahim E. Sexuality, Intimacy, and Reproductive Health after Spinal Cord Injury. Journal of personalized medicine. 2022 Dec 1;12(12):1985.
- [14] Connell, K. M., Phillips, M., Coates, R., et al., (2014). Sexuality, body image and relationships following burns: analysis of BSHS-B outcome measures. *Burns*, *40*(7), 1329-1337.
- [15] Connell, K. M., Coates, R., & Wood, F. M. (2013). Sexuality following burn injuries: a preliminary study. *Journal of Burn Care & Research*, *34*(5), e282-e289.
- [16] Corry N, Pruzinsky T, Rumsey N. Quality of life and psychosocial adjustment to burn injury: social functioning, body image, and health policy perspectives. International Review of Psychiatry. 2009 Jan 1;21(6):539-48.
- [17] Rhein, F. (2022). *The Effect of Burn Characteristics and Demographic Factors on Sexuality and Body Image* (Master's thesis).
- [18] Cato LD, Shepler LJ, McMullen K, Roaten K, Kazis LE, Ryan CM, Schneider JC. T3 Sexual Satisfaction and Association with Psychosocial Outcomes Among Burn Survivors. Journal of Burn Care & Research. 2023 May 1;44(Supplement_2):S2-3.
- [19] Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, *8*(1), 19-32.
- [20] Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MD, Horsley T, Weeks L, Hempel S. PRISMA extension for scoping reviews (PRISMA-

- ScR): checklist and explanation. Annals of internal medicine. 2018 Oct 2;169(7):467-73.
- [21] Gotschall T. EndNote 20 desktop version. Journal of the Medical Library Association: JMLA. 2021 Jul 7;109(3):520.
- [22] Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. Systematic reviews. 2016 Dec;5:1-0.
- [23] Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and quantity*, *36*, 391-409.
- [24] Hurley, A., King, I. C., Perry, F. M., et al., (2022). Addressing sexual function in adult burns victims: A multidisciplinary survey of current practice in UK burn units. *Burns*, *48*(4), 926-931.
- [25] Piccolo, M. S., Gragnani, A., Daher, R. P., de Tubino Scanavino, M., de Brito, M. J., & Ferreira, L. M. (2013). Burn Sexuality Questionnaire: Brazilian translation, validation and cultural adaptation. *Burns*, *39*(5), 942-949.
- [26] Pignanelli, M., Masschelein, G., Campbell, J., & Gillis, J. (2022). 193 Sexual Function after Burn Injury: "The Bystander Effect" and Other Results from a Survey of Active Medical Providers from the Canadian Burn Association. *The Journal of Sexual Medicine*, *19*(Supplement_1), S98-S98.
- [27] Abel, N. J., Klaassen, Z., Mansour, E. H., Marano, M. A., Petrone, S. J., Houng, A. P., & Chamberlain, R. S. (2012). Clinical outcome analysis of male and female genital burn injuries: A 15-year experience at a Level-1 Burn Center. *International journal of urology*, *19*(4), 351-358.
- [28] Levi B, Kraft CT, Shapiro GD, Trinh NH, Dore EC, Jeng J, Lee AF, Acton A, Marino M, Jette A, Armstrong EA. The associations of gender with social participation of burn survivors: a life impact burn recovery evaluation profile study. Journal of Burn Care & Research. 2018 Oct 23;39(6):915-22.
- [29] Ohrtman EA, Shapiro GD, Wolfe AE, Trinh NH, Ni P, Acton A, Slavin MD, Ryan CM, Kazis LE, Schneider JC. Sexual activity and romantic relationships after burn injury: A Life Impact Burn Recovery Evaluation (LIBRE) study. Burns. 2020 Nov 1;46(7):1556-64.

- [30] Ahmad, I., Masoodi, Z., Akhter, S., et al., (2013). Aspects of sexual life in patients after burn: the most neglected part of postburn rehabilitation in the developing world. *Journal of Burn Care & Research*, *34*(6), e333-e341.
- [31] Kazemzadeh J, Rabiepoor S, Alizadeh S. Satisfaction with appearance and sexual satisfaction in women with severe burn injuries. International journal of impotence research. 2022 Mar;34(2):215-21.
- [32] Öster, C., & Sveen, J. (2015). Is sexuality a problem? A follow-up of patients with severe burns 6 months to 7 years after injury. *Burns*, *41*(7), 1572-1578.
- [33] Akdeniz F, Şekerci ÇA, Tanıdır Y, Yılmaz Y, Çam K. Erectile dysfunction in patients with major burn injury: The significance of follow-up. Turkish Journal of Trauma & Emergency Surgery. 2022 Nov;28(11):1597.
- [34] Pandya, A. A., Corkill, H. A., & Goutos, I. (2015). Sexual function following burn injuries: literature review. *Journal of Burn Care & Research*, *36*(6), e283-e293.
- [35] Gonçalves, N., de Souza Melo, A., Caltran, M. P., et al., (2014). Sexuality in burn victims: an integrative literature review. *Burns*, *40*(4), 552-561.
- [36] Logie CH. Sexual rights and sexual pleasure: sustainable development goals and the omitted dimensions of the leave no one behind sexual health agenda. Global Public Health. 2023 Jan 2;18(1):1953559.
- [37] Fennell R, Grant B. Discussing sexuality in health care: A systematic review. Journal of clinical nursing. 2019 Sep;28(17-18):3065-76.

Figure 1: PRISMA Flowchart

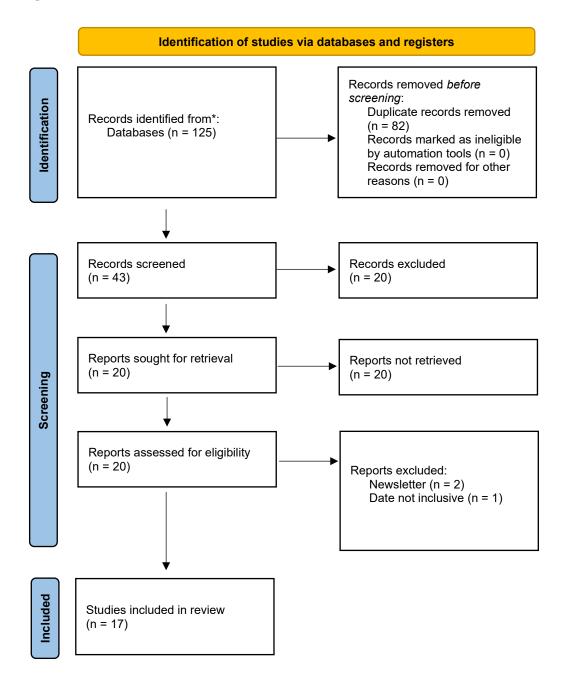


Table 1: Extracted data from included studies

Author (s)/ Year/	Study aim/ design	Focus of study	Key findings	Conclusions
Setting				
Abel, Klaassen, &	To examine the extent of	Male burn patients	Of the 111 patients included in this study, 16 patients	Males with genital burns may
Chamberlain [27]	long-term urinary and sexual	(adults)	representing 14.4% completed the survey and the	experience long term issues
	function among male genital		remaining 95 patients were unreachable. For the 16	relating to urinary and sexual
USA	burn patients.		patients who completed the questionnaire, 10 of were	dysfunction with expressions
			sexually active (3 could not maintain an erection	of anxiety and frustrations
	Retrospective study with 111		adequate for penetration and had to rely on	with sexual encounters.
	adult male burn patients and		medication; 8 had a genital scar resulting from the	
	16 burn survivors at follow-		burn; 5 reported experiencing sexual frustrations; 8	
	up		reported feeling anxious about sex; 6 felt they had lost	
			something sexually important; and 4 expressed worry	
			that their spouses or partners will feel rejected.	
Ahmad et al., [30]	To evaluate the sexual	Adult burn	Of the 544 patients interviewed, 288 patients	Longer period of
	satisfaction/ dissatisfaction in	survivors	(52.94%) responded positively to the questionnaire	recuperation may be related
India	burn survivors and factors		(score of >10), whereas 256 patients (47.05%)	to sexual dissatisfaction
	associated with this.		responded negatively (score <10). Most sexually	following burn injury survival.
			dissatisfied patients had a TBSA of 30 to 40% and	
	Cross sectional study at 6		were mostly second-degree burns.	
	months post-burn (n=544)			
			Patients admitted for less than 15 days were generally	
			sexually satisfied cases, whereas burn patients	

			admitted for more than 60 days were a significant	
			were generally dissatisfied cases.	
Aknediz et al., [33]	To examine the alteration in	Male burn patients/	The rate of erectile dysfunction demonstrated an	Male burn survivors may
	erectile functions regarding	survivors	upward trajectory at follow-up. Further analysis	experience erectile
Turkey	major burn.		showed that IIEF-5 score with electrical or flame burn	dysfunctioning in the long-
	Survey with 63 male burn patients at baseline, 3 rd , and 6 th months post-burn using the Initially International Index of ED-5 (IIEF- 5).		significantly decreased at 3 rd month compared with the baseline values.	term.
Cato et al., [18]	To determine the	Burn survivors	Older age and being single or divorced were	A significant association was
	associations of sexual		statistically significantly associated with lower sexual	found between sexual
USA	satisfaction with psychosocial		satisfaction. No association between burn size and	satisfaction and social
	outcomes and assess sexual		sexual satisfaction was observed.	integration, mental health,
	satisfaction recovery over			and post-traumatic growth.
	time after burn injury.			
	Sexual satisfaction was			
	collected at six months and			
	then every year for five years			
	post-injury using two			
	PROMIS sexual satisfaction			
	items (n=561).			

Connell et al., [15]	To examine changes in the	Burn survivors	Statistical analysis demonstrated that age and	Sexuality and body image
	sexuality and body image		sexuality subdomain of the BSHS-B were negatively	following burn injuries are
Australia	domains of the BSHS-B.		associated. Also, gender and TBSA were observed to	important quality of life
			be negatively associated with the body image	domains that should be
	Cross sectional study with		subdomain of the BSHS-B.	addressed during post burn
	burn patients following			rehabilitation.
	admission to the burn unit			
	and hospital discharge as			
	well as at 1-, 3-, 6-, and -12-			
	month time points postburn			
	injury (n=362).			
Connell et al., [9]	To examine the relationship	Female burn	The female burn survivors experienced discomfort as	Burn injuries often evoked
	between sexuality and body	survivors (n=5)	their scars were visible to others. Females who could	some behavioral changes that
Australia	image changes in burn		hide their scars mentioned they were adjusting well and	can adversely impact on
	survivors among female burn		could experience some relief. The new scarred self often	females' sexual and social
	survivors.		evoked a sense of grief or loss.	engagement.
Connell et al., [14]	To examine the impact of	A total of 1846	Women generally had lower mean BSHS-B total score	Sexuality, body image, and
Australia	burns on sexuality, body	observations from	than men with less improvement over time for minor	relationship changes occur
	image and relationship	865 burn patients	burns and a lower mean BSHS-B total score than men	over time among burn
	changes up to 24 months.	with 1846	for major burns. Within the sexuality subdomain, age	survivors.
			demonstrated a significant interaction with gender.	

		observations based	There was no significant interaction based on burn	
		on the BSHS-B	surface area and gender.	
			3	
		Up to 24 months		
		post-burn		
Goncalves et al., [35]	To analyze and synthesize	Adult burn patients/	Two key findings emerged: studies that explored post-	Post-burn sexual challenges
	knowledge concerning	survivors	burn sexuality and those that explored sexuality	may be related to burn
	sexuality in adult burn		indirectly.	survivors of younger age,
	patients/ survivors			burn surface area > 20%,
				injuries to the genitalia and
	Integrative review with 22			on exposed areas, prolonged
	included studies			hospitalisation, avoidance
				coping, and existence of
				mental health issues.
Hurley et al., [24]	To examine the management	Burn care	79% of the participants described post-burn sexual	No standardized approach
	approaches of sexual	practitioners	function as an important, yet unaddressed issue in	exists in addressing post-
United Kingdom	functioning following		current practice. Despite this great need, 90% of the	burn sexual concern.
	surviving burn injuries.		burn care practitioners noted that never occasionally	
			ask their burn patients and often, there is no specific	
	Cross-sectional survey		practitioner assigned to lead this area of care.	
	(n=56)			
Kazamzadeh et al.,	To examine the relationship	Adult female	82% of the female participants with severe burns	Interventions are needed to
[31]	between appearance and	burned patients.	reported lower levels of sexual satisfaction. It was	improve appearance
	sexual satisfaction among		observed that a female burn survivor's satisfaction with	satisfaction in females with

Iran	females with severe burn		her appearance had a significant negative relationship	severe burns, and
	injuries.		with sexual satisfaction	subsequently their body
				image.
	Cross-sectional survey with			
	180 female burned patients.			
Levi et al., [28	To examine the associations	Burn survivors	Males scored better than females on four LIBRE profile	Females fare less in several
	of burn injury on community		scales (Sexual Relationships, Social Interactions, Work	domains of the LIBRE profile
USA	reintegration based on		& Employment, and Romantic Relationships).	following burns and should
	gender.			be considered in post-burn
				intervention support.
	Life Impact Burn Recovery			
	Evaluation (LIBRE) Profile			
	(n=601).			
Ohrtman et al., [29]	To examine the demographic	Adult burn	Adult burn survivors were more likely to report being	Adult burn survivors are
	and clinical characteristics	survivors	active sexually than in the matched general sample.	likely to engage in sexual
USA	predicting engagement in		Participants in both groups who were not working	activity and romantic activity
	sexual activity and romantic		were less likely to report being in a romantic	just as the unburned group.
	relationships in a sample of		relationship or being sexually active. TBSA, time since	
	adult burn survivors		occurrence of burns, and burns to other significant	
	compared to a general		pars were not associated with being in a romantic	
	United States sample.		relationship or being sexually active.	
	Life Impact Burn Recovery			
	Evaluation (LIBRE) Profile			

	(n=601) and 2000 adults			
	through sample matching.			
Oster & Sveen [32]	The aim was to ascertain	Adult burn	Males were more satisfied than females, though the	The BSHS-B sexuality
	sexuality in adult burn	survivors	sexual subdomain scores improved up to 7 years in	subdomain may be a useful
Sweden	survivors using the BSHS-B		both genders. Factors that strongly contributed to poor	tool to screen burn survivors.
	sexuality subscale and to		sexuality outcomes include having a history of	
	examine possible		psychiatry morbidity, severity of the burns, and	
	contributing factors with		neuroticism.	
	regard to sociodemographics,			
	burn characteristics,			
	personality traits, and			
	previous psychiatric			
	disorders.			
	Cohort study of (n = 107)			
	followed up at 6, 12, and 24			
	months after burn, and 67			
	individuals were followed up			
	at 2–7 years after burn.			
Pandya, Corkill, &	To review the literature	Burn survivors	Factors that may affect the quality of post-burn sexual	A holistic approach is needed
Goutos [34]	regarding post-burn sexual		functioning include age at the time of injury, location,	to manage the post-burn
	functioning		and severity of the burn, and coping mechanism.	sexual and intimacy issues.
	Literature review			

Piccolo et al., [25]	To examine how Brazilian	Burn care staff	Few (28%) of the burn care staff were comfortable in	There is a significant lack of
	burn care staff navigate		discussing post-burn intimacy issues with the majority	studies exploring the post-
Brazil	sexuality issues after burn		highlighting that it should be the work of the	burn sexuality and intimacy
	injuries		psychologist.	concerns.
	Cross sectional study			
	(n=124)			
Pignanelli et al., [26]	To examine the patterns of	Burn care	Several participants [47% (n=15) and 36% (n=11)] of	Burn care staff are not
	practice and views regarding	practitioners	participants indicated that "it is not anyone's	adequately addressing the
Canada	sexual functioning after		responsibility" in response to discussing sexuality in	post-burn sexuality and
	burns		inpatient and outpatient units respectively. Most	intimacy concerns.
			participants (n=26, 84%) noted that their burn teams	
			did not do a good job at addressing the post-burn	
			sexuality and intimacy issues.	
	Cross sectional survey			
	(n=32)			
	A 24-item survey; modified			
	from a survey created by			
	Rimmer et al, 2010			
Rimmer et al., [10]	To examine current practices	Burn care	Almost half of the participants (47%) reported that no	Burn care staff are not
	of discussing post-burn	practitioners	staff was assigned to lead the discussion of post-burn	adequately addressing the
USA	sexual and intimacy issues		sexual and intimacy issues. Up to 62% of the	post-burn sexuality and
			participants underscored the lack of training in this	intimacy issues and several

Cross-sectional	survey	area. Fifty-five percent noted that they were only likely	factors seem to contribute to
(n=71)		to discuss sexuality and intimacy if the patient or their	this.
		partner initiated the discussion.	