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Research Article

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Ensuring that the outcome domains proposed for use in burns research are relevant to adult burn patients: a systematic review of qualitative research evidence

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Abstract

Background: There have been several attempts to define core outcome domains for use in research focused on adult burns. Some have been based in expert opinion, whilst others have used primary qualitative research to understand patients' perspectives on outcomes. To date there has not been a systematic review of qualitative research in burns to identify a comprehensive list of patient-centred outcome domains. We therefore conducted a systematic review of qualitative research studies in adult burns.

Methods: We searched multiple databases for English-language, peer-reviewed, qualitative research papers. We used search strategies devised using the SPIDER tool for qualitative synthesis. Our review utilized an iterative three-step approach: (1) outcome-focused coding; (2) development of descriptive accounts of outcome-relevant issues; and (3) revisiting studies and the broader theoretical literature in order to frame the review findings.

Results: Forty-one articles were included. We categorized papers according to their primary focus. The category with the most papers was adaptation to life following burn injury (n = 13). We defined 19 outcome domains across the 41 articles: (1) sense of self; (2) emotional and psychological morbidity; (3) sensory; (4) scarring and scar characteristics; (5) impact on relationships; (6) mobility and range of joint motion; (7) work; (8) activities of daily living and self-care; (9) treatment burden; (10) engagement in activities; (11) wound healing and infection; (12) other physical manifestations; (13) financial impact; (14) impact on spouses and family members; (15) analgesia and side effects; (16) cognitive skills; (17) length of hospital stay; (18) access to healthcare; and (19) speech and communication. We suggest that sense of self is a core concern for patients that, to date, has not been clearly conceptualized in the burns outcome domain literature.

Conclusions: This outcome domain framework identifies domains that are not covered in previous attempts to outline core outcome domains for adult burn research. It does so with reference to existing theoretical perspectives from the sociology and psychology of medicine. We propose that this framework can be used as a basis to ensure that outcome assessment is patient-centred. Sense of self requires further consideration as a core outcome domain.

Key words: Outcome domains, Adult burns, Qualitative research, Systematic review

Background

In 2004, Pereira and colleagues questioned whether mortality was redundant as an outcome measure in burns care and research, suggesting that other intermediate and long-term outcomes were now more significant due to improvements in survival [1]. They posited that outcomes such as length of stay (LOS), determinants of hypermetabolic response, exercise tolerance and quality of life (QoL) should also be considered. Since then, there have been attempts to define core outcome domains for research focused on adult burn survivors. The nature of these exercises has differed. For example, Falder *et al.* [2] derived a framework of seven core outcome domains via a process involving clinical experts. Other researchers have utilized primary qualitative research techniques to understand patients' perspectives on these issues—for example, as part of the development of conceptual models of health-related QoL [3, 4], or whilst identifying outcome domains relevant to patients during scar management therapy [5]. The use of qualitative research techniques to understand patient perspectives recognizes that views on relevant outcome domains may differ between clinical and patient stakeholders. This type of research has been used as a basis to identify and reflect on the conceptual content of available outcome measures [2, 5], or to form part of the development process for novel measures [3]. Whilst individual primary qualitative studies have been used, to date, there has not been a systematic review of the wider body of qualitative research in burns to identify a comprehensive list of patient-centred outcome domains. Conducting such a review is important, as individual primary qualitative studies cannot necessarily lay claim to broad generalisability and applicability [6]. Thus, where there is a suitable existing body of primary qualitative research studies, a systematic review may be better able to provide a comprehensive view of outcome domains that are of importance to patients. We therefore conducted a systematic review of qualitative research studies in adult burns research aiming to identify a comprehensive list of outcome domains that are of importance to adult burn patients.

Methods

The reporting of our methods is in concordance with guidance for the reporting of qualitative synthesis in health research settings [7].

Literature searches

Informed by the SPIDER tool for qualitative synthesis, strategies were employed to maximize the identification of relevant literature [8–10]. We searched electronic databases (MEDLINE; MEDLINE In Process; Embase via Ovid; Social Sciences Citation Index via Web of Science; and CINAHL via EBSCO) and the reference lists of included papers were also searched. No date limits were applied to the searches (i.e. from database inception), which were run until the end of October 2017 (see Table S1).

Selection criteria

We included English-language papers published in peer-reviewed journals that reported using qualitative research methods with adult burn patients. We included all papers that met these criteria, not just primary studies with an overt focus on patient perspectives on outcome domains. For example, qualitative research papers focusing on patients' views of their appearance following burns would be eligible for inclusion in this review. Included papers had to report the findings of a qualitative analysis of data collected using qualitative-data-collection methods, such as interviews, focus groups or non-participant observations. Papers were excluded if they: focused exclusively on paediatric burns; focused exclusively on mixed clinical populations without an explicit focus on burns (e.g skin conditions); reported rare occurrences or specific clinical groups; focused on a pre-burn event or cause of the burn (i.e. not containing data relevant to outcomes post-event); or explored the views of healthcare professionals. Mixed-methods papers meeting these criteria were included.

Screening

Following the removal of duplicates, the titles and abstracts of articles were screened by JT and JM. Articles not meeting the above criteria were excluded. Full-text versions of the remaining articles were reviewed by JT and JM.

Quality assessment

We have included all papers that met the inclusion criteria defined above. This is because we judged that all relevant qualitative research studies had the potential to contribute conceptual content to the development of the outcome domain framework presented here. There continues to be significant debate around the quality appraisal of qualitative research studies, and particularly the uncritical use of quality checklists in qualitative systematic reviews [11, 12]. Additionally, there is little evidence demonstrating that judgements of the quality of reporting of qualitative research adequately reflects underlying robustness, trustworthiness and transferability [7]. Our view is that studies judged as relatively poorly reported in quality appraisal checklists might still be conceptually rich, therefore providing important contributions to the review. Nevertheless, we used the critical appraisal skills programme (CASP) qualitative checklist to provide a judgement as to whether included papers were well reported or not.

Data extraction

Key characteristics of studies were extracted, including authors, title, journal, year of publication, study aims, sample characteristics, setting, data collection methods and analytical methods. Data were coded for outcomes (see data analysis section) in QSR NVivo (Version 11) https://www.qsrinternational.com/contact-us. We coded the authors' descriptive text, as well as primary data in the form of quotations. This was undertaken jointly by JT and JM for all the papers identified.

Data analysis

Qualitative systematic review and synthesis techniques are now well established, with a number of methodological approaches [13]. However, to date, their use to identify outcome domains suitable for quantitative outcome research is novel, and a clear methodology for this specific purpose has not yet been described in detail. Our review approach was based upon an iterative three-step process that would most closely align with thematic synthesis [14]: (1) outcome-focused coding; (2) development of descriptive accounts of outcome-relevant issues identified from step 1; and (3) revisiting studies and the broader theoretical literature in order to frame the review findings. As part of step 1, we coded each paper line by line. This was done inductively from the data. However, whilst not a deductive framework applied top-down to the data, we were sensitized to outcomes that had already been discussed in the literature; for example, within the review article by Falder and colleagues [2], via previous work from our group focused on outcomes during burn scar management [5] and via consultation with clinical colleagues in burns care and research. Our definition of a patient-centred outcome is broad and includes things that would be recognizable as endpoints to burns clinicians and researchers, as well as any consequence of burn injury or treatment that may have significance to adult burn patients. The initial coding framework was developed iteratively as data extraction proceeded. No new codes or concepts were being identified within papers at the end of this process. Descriptive accounts written during step 2 enabled rationalization of this coding and identification of overlap and interrelationship in concepts. This process allowed us to move towards a near-finalized outcome domain structure relating to the included papers. In the final step, the broader theoretical literature, particularly from the sociology and psychology of medicine related to the impacts of and adaptation to chronic disease, was used for interpretive purposes and to inform final categorization into outcome domains and items. We then applied our final outcome domain categorization once again to the entire dataset to reassess fit with the data contributing to the review.

Results

Summary of included papers

Electronic searches identified 411 articles following the removal of duplicates (Figure 1). Following title and abstract screening, 80 articles went forward for full-text review. Of these, 39 were excluded for the following reasons: paediatric population (n = 21), conference abstract only (n = 2), not English language (n = 1), not burn-specific (n = 5), focused on burn event or pre-burn (n = 3), rare occurrence (n = 3), not qualitative research (n = 2) and focused on carers' views (n = 2).

Forty-one articles were consequently included in this review (Table S2). We categorized the 41 papers according to their primary focus. The category with the most papers was adaptation to life following burn injury (n = 13) [15–27], followed by research focused on the experience of specific treatments (n = 9) [5, 28–35], relating to a specific group or demographic (n = 7) [36–42], social issues and relationships (n = 4) [43–46], experience of pain (n = 3) [47–49], return to work (n = 3) [50–52] and QoL (n = 2) [3, 53]. Of the 41 papers included, 36 were judged to be well reported using the CASP qualitative checklist (Table S2).

Core outcome domains

In Table 1, 19 outcome domains resulting from analysis of the included articles and details the prevalence of these domains across the articles. In descending order of prevalence, these domains are: (1) sense of self; (2) emotional and psychological morbidity; (3) sensory; (4) scarring and scar characteristics; (5) impact on relationships; (6) mobility and range of joint motion; (7) work; (8) activities of daily living and self-care; (9) treatment burden; (10) engagement in activities; (11) wound healing and infection; (12) other physical manifestations; (13) financial impact; (14) impact on spouses and family members; (15) analgesia and side effects; (16) cognitive skills; (17) length of hospital stay; (18) access to healthcare; and (19) speech and communication. Whilst survival (mortality) is represented in the qualitative literature reviewed, we have not included this as a listed outcome domain as this review was focused on the outcomes of burn survivors.

We will first provide a detailed description and interpretation of the first and most prevalent outcome domain, sense of self, before describing the other outcome domains more briefly. We do this as we posit that sense of self is a core concern for patients that has not been clearly conceptualized in the burns outcome domain literature to date, particularly in relation to theoretical insights concerning adaptation to chronic disease provided by the sociology and psychology of medicine. We will also provide a comparison between the domain framework presented here and those proposed in previous work.

Sense of self Components of this domain occurred in 39 of the 41 articles included in the review. Burn injury and the need for rehabilitation can constitute a fundamental psychological threat to patients' self-image (their sense of self). Kelly, in his

Table 1. Outcome domain prevalence across the included articles

	Access to healthcare	ADL & self-care	Analgesia & side effects	Cognitive skills	Emotional & psycho-logical morbidity	Engagement in activities	Financial impact	Impact on spouses and family	Length of hospital stay	Mobility and joint range of motion	Other physical manifesta-tions	Impact on relation-ships	Scarring and scar character-istics	Sense of self	Sensory	Speech & communi-cation	Treatment burden	Work	Wound healing & infection
Abrams *et al* (2016) [15]		X			X	X		X	X	X	X	X	X	X	X		X		X
Badger & Royse (2010) [28]					X							X		X	X				
Barnett *et al* (2017) [29]					X				X			X		X			X		
Burnett *et al* (2014) [32]						X				X			X	X	X		X		
Ciofi-Silva *et al* (2010) [16]					X	X	X			X	X	X	X	X	X				
Connell & Wood (2015) [43]		X			X	X	X					X	X	X			X		X
Dahl *et al* (2012) [17]		X	X		X			X		X	X	X	X	X	X		X		X
Davis *et al* (2014) [31]					X								X	X	X				
Dunpath *et al* (2015) [41]		X			X					X		X	X	X	X				X
Giordano MS (2016) [45]					X							X	X	X					
Gullick *et al* (2014) [35]		X	X	X	X		X	X				X	X	X	X	X			X
Hunter *et al* (2013) [36]		X			X			X		X		X	X	X	X				X
Johnson *et al* (2016) [27]		X	X	X	X		X	X		X	X	X	X	X	X				X
Jones BA *et al* (2017) [37]	X				X					X		X	X	X	X			X	
Jones *et al* (2017) [5]					X	X	X	X		X		X	X	X	X		X		
Khoshnami *et al* (2017) [38]					X		X	X			X	X	X	X	X		X		
Kornhaber *et al* (2014) [18]		X			X	X							X	X	X				X
Kornhaber *et al* (2015) [30]					X								X	X			X		
Lau & van Niekerk (2011) [20]					X	X						X	X	X	X				
Mackey *et al* (2009) [50]					X		X			X	X		X	X	X		X		
Macleod *et al* (2016) [21]					X	X						X	X	X					
Martin *et al* (2016) [33]		X			X	X				X	X	X	X	X	X		X		X
Martin *et al* (2017) [46]					X			X				X	X	X	X		X		
Moi & Gjengedal (2008) [19]		X	X	X	X	X	X			X		X	X	X	X		X		X
Moi & Gjengedal (2014) [44]	X	X	X	X	X	X	X	X				X	X	X	X		X	X	X
Moi *et al* (2008) [22]		X	X	X	X	X	X	X		X	X	X	X	X	X		X		X
Nguyen *et al* (2016) [51]		X			X		X			X	X	X		X	X		X		X
Norouzi *et al* (2012) [42]	X				X			X					X	X			X	X	
Oster *et al* (2010) [52]	X		X		X		X			X	X	X	X	X	X		X	X	
Pérez Boluda *et al* (2016) [47]		X	X		X					X	X			X	X				X
Rahzani *et al* (2009) [39]					X	X						X	X	X	X				
Ren *et al* (2015) [23]		X			X			X		X	X	X	X	X	X		X		X
Rossi *et al* (2009) [53]		X			X	X	X	X		X		X	X	X	X		X		X
Simons *et al* (2016) [3]		X		X	X	X		X		X		X	X	X	X		X		X
Song & Oh (2016) [34]										X					X		X		
Tengvall *et al* (2010) [48]		X	X		X				X	X	X		X	X	X		X		X
Thakrar *et al* (2015) [40]		X	X		X	X				X		X		X	X				X
Williams *et al* (2003) [24]		X			X			X	X	X	X	X	X	X	X		X		X
Yuxiang *et al* (2012) [49]		X	X								X				X				X
Zamanzadeh *et al* (2015) [25]		X			X	X	X	X		X	X	X	X	X	X				X
Zhai *et al* (2010) [26]		X			X		X			X		X	X	X	X				X
Total, n(%)	4/41 (10%)	23/41 (56%)	11/41 (27%)	6/41 (15%)	38/41 (93%)	17/41 (41%)	15/41 (37%)	16/41 (39%)	4/41 (10%)	25/41 (61%)	16/41 (39%)	31/41 (76%)	34/41 (83%)	39/41 (95%)	35/41 (85%)	1/41 (2%)	23/41 (56%)	24/41 (59%)	17/41 (56%)

ADL activities of daily living

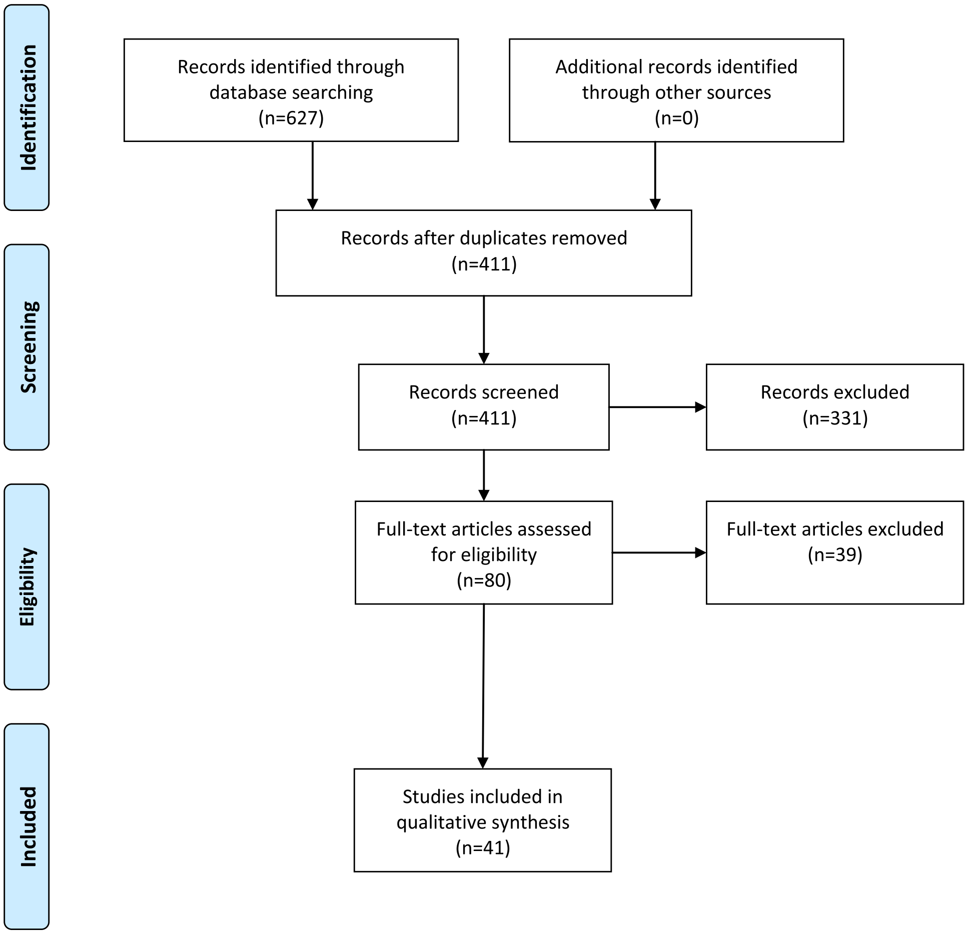

Figure 1. PRISMA flow diagram

work focused on living with UIcerative Colitis defines the self as:

> *'At its simplest the term "self" refers to the inner and private view an individual has of him- or herself … Self is subjective; it is about our sense of who and what we are, it helps locate us in the world we live; that is, we are someone with particular characteristics, feelings and loyalties … It is essential for psychological functioning and it develops and changes with experience.'* [54]

This threat to self is a key component of sociological theories concerning the significance for patients of the consequences (outcomes) of illness, demonstrated in work focused on injuries [55] and other debilitating chronic conditions [56–60]. The terms rehabilitation, or sometimes reintegration, are common in the burns literature. We are suggesting that the idea of patients reworking their sense of self is concordant with a holistic notion of rehabilitation. Adaptation to chronic disease has been studied and theorized both in the sociology and psychology of medicine [61, 62]. It is beyond the scope of this article to provide a review of the theories of different disciplines, but our outcome-focused interpretation here is influenced by work concerning threats to the self in medical sociology and psychological theories of adaptation, particularly theories of stress and coping [62].

We are suggesting that this domain be considered as clearly distinct from emotional and psychological morbidity. Whilst the latter may be associated with a disrupted sense of self, the absence of psychological morbidity is not, in itself, indicative of psychological adaptation to burn injury. Rather, we use the concept of a disrupted sense of self to describe a common response to burn trauma that is independent of psychological morbidity. We identified codes that represent two components of this domain: (1) indicators of a threat to sense of self and (2) coping mechanisms and strategies (Table 2). In turn, these relate to reworking a sense of self.

Several items may be considered indicators of a threat to sense of self (Table 2). These include reports of grief and mourning for losses incurred (e.g. physical, activity-related, autonomy) and of uncertainty regarding the future. They also include appearance-related concerns, including anxiety over perceived social reactions and feelings that an appearance-altered state is a defining characteristic of self, as well as a sense of role disruption and of dependence and impact on significant others. We have also categorized body image

Table 2. Components of the "sense of self" domain

Threat to sense of self – indicators of this
Appearance-related concerns, e.g. anxiety related to perceived and actual social reactions; feeling that visible differences are self-defining characteristics; body image and confidence
Fear of rejection
Feeling of insecurity and/or disability (in hospital and post discharge)*
Feeling of isolation in hospital when separated from significant others*
Lack of recollection of accident/in-hospital period*
Grief for losses incurred as a consequence of the burn injury
Sense of role disruption, e.g. work, within family
Sense of dependence and impact on significant others
Sense of otherness
Sense of vulnerability
Stigma
Uncertainty regarding the future
Coping mechanisms and strategies
Acceptance (acknowledgement of the injury and how this might impact on life)
Accessing healthcare professional support
Accessing peer support/social support
Adaptive planning of how to behave in relation to social reactions—e.g. use of humour, attempts to see things from others' perspective; focusing on stable aspects of self; use of social media/online platforms
Appreciating the important things, e.g. family, friends
Comparison with others with more severe burn injuries
Emotional expression/suppression
Exposure to anxiety-provoking stimuli
Finding new meaning in relationships (strengthening/reframing)
Goal setting (including testing boundaries, empowerment and self-efficacy)
Maladaptive actions in relation to social reactions—situational avoidance and isolation; covering scars and/or avoiding looking at them; closed body language; alcohol; emotional suppression
Making physical adaptations
Positive growth and transformation, e.g. tolerance and respect for others, taking on new roles (with burns organizations/survivors/within families); positive self-appraisal, e.g. adopting burn survivor identity; incorporating scars into life story
Positive thinking
Religion/faith
Self-care/management—empowerment
Treatment dependence, e.g. pressure garments providing protection—second skin
Indicators of adaptation
Reconstituted sense of self; positive identity; reframed sense of normality

*Relevant to acute/inpatient care

and confidence here as being indicative of damage or threats to self. These indicators also include factors that might be relevant to acute inpatient care, such as feelings of insecurity or isolation in hospital—factors that have been linked with threats to sense of self in work focused on injuries [55]. Where these indicators can be assessed, they may signal where patients are located in their psychological journey and be indicative of a need for support or intervention.

Second, we have coded a number of coping mechanisms and strategies apparent from the review (Table 2). Coping is a key component of psychological theories of adaptation to the stresses placed upon patients by chronic conditions [62]. In terms of assessment, these might be considered as process measures indicative of how patients are attempting to achieve adaptations, or as outcomes in their own right for interventions that aim to provide patients with productive coping mechanisms.

Ultimately, adaptation (where attainable), may be indicated by a reworked sense of self, a reported sense of normality in life or a reframed identity (Table 2). Kelly defines the latter as follows.

> *'Identity is about social relationships. In any social arrangement people occupy positions, statuses and roles. These are the markers by which self is identified by other people. Identity establishes what and where the person is in the social structure … Identity then is a label imposed by others on self.'* [54]

Where these can be assessed, they may be considered key long-term and overarching endpoints indicative of psychological adaptation.

Emotional and psychological morbidity, present in 38 of the articles, encompasses emotional wellbeing (e.g. anger, fear, sadness), clinical depression and the occurrence of post-accident trauma and distress. The latter includes hypervigilance related to the potential for further burn injury. Participants in some studies also referred to suicide and attempted suicide, which is included as an item in this domain.

The sensory domain (35 articles) includes itch and pain, distinguishing pain from the injury and wound from that was induced by treatment (item: treatment and procedural pain).

This domain also includes anxiety and emotional distress associated with pain, factors that have also been identified as significant in terms of their psychological impact and threat to sense of self [55]. Other items in the sensory domain include skin sensitivity, the ability to regulate temperature and sensitivity to temperature changes.

Scarring and scar characteristics (34 articles) includes two items, scar appearance and scar characteristics. Scar appearance describes adult patients' subjective views of their scarring and is closely related to the item 'appearance-related concerns' that is described in the sense of self domain. The articles reviewed also discussed patients' descriptions of specific scar characteristics such as scar texture, thickness and colour.

Impact on relationships (31 articles) includes impacts on spousal relationships, such as intimacy and sexual relationships, as well as impact on other intra-family relationships. Papers also detailed impacts on friendships and social relationships and the potential for post-burn injury isolation and loneliness.

Mobility and range of joint motion (25 articles) includes the ability to move about freely (mobility), joint range of motion, the incidence of contractures or tightness and the ability to use hands and limbs.

The work domain (24 articles) covers return to work following injury and the need to modify work-related tasks.

Activities of daily living and self-care, identified in 23 papers, also includes sleep and sleep disturbance.

Treatment burden (23 articles) describes both objective (number of appointments and length of active treatment) and subjective elements (perceived cumulative burden of treatments and effort associated with treatments) of burden associated with treatment and rehabilitation.

Engagement in activities (17 articles) includes hobbies, sports and social and educational activities.

Wound healing and infection (17 articles) includes the incidence of wound infection, time to wound healing and patients' feelings of vulnerability and fragility associated with skin or wounds.

The other physical manifestation (16 articles) domain includes the items fatigue, muscle strength and endurance, appetite, eyesight, fever and oedema.

Financial impact and the impact on spouses and other family members as a consequence of the burn injury were identified in 15 and 16 articles, respectively.

Analgesia and side effects (11 articles) describes the availability and appropriate administration of analgesia, along with side effects and symptoms of withdrawal from analgesia.

Cognitive skills (6 articles) describes the ability to concentrate, along with memory and memory loss.

Length of hospital stay (4 articles) and access to healthcare (4 articles) includes the availability of acute and non-acute care and waiting times for non-acute care.

Speech and communication were only identified in a single article.

Many of these domains are relevant to acute inpatient care. These include some components of sense of self (feelings of insecurity and isolation in hospital; lack of recollection of hospital period), wound healing and infection, sensory outcomes (procedural pain and associated anticipation and anxiety), analgesia (availability/administration of and side effects), speech and communication (the ability to communicate following injury in an inpatient setting), cognitive skills (concentration and memory loss) and also length of hospital stay.

Comparison with other outcome domain frameworks

Table S3 provides a comparison between the outcome domain framework proposed here and previously proposed frameworks [2, 4, 5]. Sense of self was not covered in Falder *et al.* [2], only psychological morbidity (depression and trauma). There is some overlap with the categories of resilience and vulnerability in Kool *et al* [4], but the domains specified within these categories do not adequately cover all of the components of the sense of self domain described here. Whilst Jones *et al*'s psychological distress, adjustments and sense of normality is coherent with the sense of self domain, it is not theoretically articulated [5]. Some of the outcome domains detailed from our review are not covered in any of these domain frameworks (analgesia and side effects of analgesia; speech and communication; length of hospital stay; access to healthcare). Some items are also not represented in previous frameworks (e.g. feeling of vulnerability and fragility of skin or wounds; non-normal skin sensations). Whilst treatment burden was also detailed in Jones *et al.* this is not a part of the Falder or Kool *et al.* frameworks. Some items included in Falder *et al.* were not identified specifically in the qualitative literature, such as sepsis, need for reconstructive surgery, balance or cardiovascular fitness.

Discussion

We have provided the first comprehensive outcome domain framework derived from a systematic review of existing qualitative research studies in adult burns. We have identified 19 outcome domains relevant to patient-centred assessment in burns research. We have intentionally left the domain framework presented here disaggregated. That is, we have not suggested an aggregated structure based upon higher-order domains or categories, for example, physical or psychological health or functional ability. This is because we believe that definitions of such higher-order domains are often open to interpretation and not necessarily concordant across different domain frameworks or conceptual models [63, 64]. We also wanted to provide a framework that took account of broader theoretical insights into the patient experience of injuries and chronic conditions, and so decided that higher-order domain structures derived for other purposes were not necessarily concordant with such a theoretical interpretation. In deriving this domain framework from existing qualitative research studies we have been inclusive in our approach. We have included all domains that are evident in the qualitative literature reviewed, not just those that are most prevalent.

Sense of self was prominent in the adult burns qualitative literature. We would argue that, to date, this concept has not been robustly incorporated in attempts to outline core outcome domains for burns research. Here we propose that this domain encompasses indicators of a threat to sense of self and coping mechanisms and strategies, which, in turn, influence a reworking of a sense of self after burn injury. In particular, conceptualizing the holistic impact of burns injury as a threat to self (self-image), necessitating adaptation and reworking of the self (a holistic notion of rehabilitation), is informed by theoretical views from the sociology and psychology of medicine [55–57, 60, 62, 65]. A number of the qualitative papers in our review addressed the need for those with a burn injury to rework their sense of self (e.g. [18, 20, 25, 27, 31]). However, only Lau and Niekerk [20] in their study of young burn survivors in South Africa have explicitly referred in detail to the sociological theories employed here.

Several of the indicators of threat to self that are apparent in the qualitative burns literature are already recognized as key influences on psychological wellbeing, for example, feelings of in-hospital anxiety, isolation and distress [66–68] and appearance-related concerns [69]. Similarly, coping mechanisms and strategies have been identified as an influence on psychological adjustment in burns [66]. Psychological adjustment post-burn injury has, in recent years, received more attention in the burns research literature [66, 69, 70]. It goes beyond psychopathology and the assessment of this, but there has not yet been a unified approach to the measurement of adjustment [70]. A clear relationship between the extent and location of burn injury and adjustment has not been well established [66]. Bosmans *et al.* [71] examined the role of coping self-efficacy in recovery from traumatic stress following burn injury. They concluded that burn severity was not associated with post-traumatic stress disorder symptoms or recovery, but that coping self-efficacy and emotional expression (a form of coping style that is evident in the qualitative literature and detailed here) were, and that they were also possible foci for intervention. Elsewhere, coping has been recognized as a useful concept in chronic illness to understand illness adjustment or as a focus for intervention to aid adjustment [72, 73]. It is a core component of psychological models of stress and coping that have been used to understand adaptation to chronic illness [62].

Other than psychological adaptation, we have interpreted a range of domains, including those that describe broader impacts resulting from burn injury (e.g. work, relationships), as well as more clinically focused outcome domains, such as wound healing and infection, scarring and scar characteristics and sensory outcomes, such as pain and itch. In reviewing the qualitative literature we have identified potential outcome domains and items that were not included in three previous attempts to define core outcome domains for assessment in burns research: the availability of analgesia and the side effects of analgesia, speech and communication, length of hospital stay and access to healthcare were domains not represented in any of these previous frameworks. Other items apparent in qualitative research studies, such as a feeling of vulnerability or fragility of skin or wounds, were also not detailed in previous work. As two of these prior frameworks [4, 5] utilized primary qualitative research methods, this implies that reviews of qualitative research not designed to focus on identifying outcome domains, rather than reliance on individual primary studies, are likely to result in a broader and more comprehensive domain framework. As per emerging insights in other clinical areas, systematic reviews of qualitative studies are also likely to identify outcome domains and items that are different to those traditionally used in clinical trials and other research studies [74].

Some of the items discussed in the review by Falder and colleagues [2] were not identified within our review (sepsis; need for reconstructive surgery; balance; cardiovascular fitness). Similarly, Perreira and colleagues [1] suggested measurement of determinants of hypermetabolic response that were not identified here. Naturally, certain clinical and biomedical outcomes will not be at the forefront for patients when participating in qualitative research studies. Thus, expert clinical input to identify other relevant clinical and biomedical outcomes is necessary alongside work such as this. Currently, other work is being undertaken to develop a core outcome set for burn care that will incorporate the views of clinical experts as well as patients and other stakeholders [75]. Our review is complementary to work such as this, in providing a comprehensive view of outcome domains of importance to patients. As core outcome sets are arrived at via consensus methods they will not necessarily contain all domains that have relevance to patients as detailed in reviews of qualitative research such as this.

Other than providing a comprehensive review of previous qualitative research studies, our work also attempts to derive a more theoretically driven interpretation of the outcome domain framework presented. This has focused on the sense of self domain, which could be considered a core, overarching outcome domain influenced by many, if not all, of the other domains presented. By drawing on theoretical work to understand the holistic impact of burn injury and treatment as a potentially fundamental threat to patients' sense of self, and the process of adaptation and reworking as a fundamental endeavour for patients, we can clearly articulate the core medium- and long-term patient-focused concerns. We can also start to make links with short-term, acute outcomes, such as the ability to communicate, memory loss, the side effects of analgesia, anxiety and anticipation of procedural pain and feelings of isolation in inpatient settings, which have been linked to threats to sense of self [55].

In our review we have not referred to or attempted to identify components of QoL. As Falder and colleagues [2] commented, there are multiple measures of QoL available, with various content items, which is a result of the varied definitions and conceptualizations of QoL. Kool *et al.* [4], in their work focusing on patients' perspectives on QoL after burn using qualitative research techniques and cluster analysis, identified two broad categories of burn-related QoL: resilience and vulnerability. We would suggest that a more theoretically informed, rather than statistically derived, interpretation of items identified via the focus groups and interviews conducted by Kool *et al*., might suggest that the vulnerability category contains many things that threaten sense of self and that the resilience category partially identifies coping mechanisms and strategies. QoL models, such as that proposed by Kool *et al*., are therefore implicitly identifying components of health-related QoL that, conceptually, might be considered psychological adaptation. However, without explicit theoretical interpretation of the significance of outcome domains and their components, this remains implicit. There are two issues with this. First, we would contend that whilst sense of self may be considered a core, overarching domain, it is not conceptually equivalent to health-related QoL as implied by Kool *et al*.'s [4] use of resilience and vulnerability categories. Second, because a number of QoL measures are being used in burn research, without in-depth reflection regarding the meaning and conceptual content of QoL we are in danger of assuming that if a measure of QoL is included in research studies then we are automatically assessing outcomes from a patient-centred perspective. Unless QoL tools and measures clearly distinguish sense of self as a component of QoL this will not be the case. This issue has been recognized in other quarters, for example with a recent call to incorporate psychological adjustment expressly within the International Classification of Functioning, Disability and Health [76]. Additionally, we would argue that there is a need to consider how broader theoretical insights into the experience and meaning of living with chronic conditions, including burn injuries, can be integrated into assessment and measurement tools. Outside of burn research some authors have started to consider how conceptual insights from broader theoretical work, for example, in medical sociology, can be brought together to understand how patients attempt to live with chronic illness [77]. This work has started to examine tools available to assess the concept of living with a chronic illness [78]. This is concordant with our suggestion that sense of self (psychological adaptation) to burn injury be considered a core outcome domain.

Strengths and limitations

This is the first systematic review of qualitative research studies in burns to focus on outcome domains relevant to patient-centred assessment in burns research. It is based upon a large body of qualitative evidence gathered across various settings and adult burn patient populations. It has utilized a review process incorporating well recognized analytical approaches that are commonly used with primary qualitative research data (coding, descriptive accounts, iterative development of interpretations). A significant strength and novel aspect of the review is the application of theoretical perspectives to demonstrate the core overarching meaning of burn injury to adult patients and therefore why sense of self should be considered as a core outcome domain in burns research. As with any systematic review we are limited by available qualitative evidence and in particular as the majority of studies included in the review were not undertaken from an overt outcomes perspective, by the focus of the papers included. As papers on rehabilitation post-burn injury were the most common category of papers identified it might be argued that this has skewed the focus of our domain framework towards an interpretation that places psychological adaptation at the heart of it. However, we would argue against this, particularly because the psychological impact of burns is already well recognized and psychological adaptation has received more attention in the burns research literature, even if this has not been reflected in previously proposed outcome domain structures. Issues relevant to adaptation were also evident in papers from studies that did not expressly set out to focus on rehabilitation and adaptation. Our literature searches were concluded towards the end of 2017. However, we reached a point where new outcome domain codes and concepts were not being identified. In other words, we attained conceptual saturation in our domain framework and the review of additional papers published since our original searches would not substantively change the findings presented. We have included all papers identified regardless of the judgement of quality of reporting provided using the CASP qualitative checklist. However, only five of the included papers were judged to be less well reported using CASP, which should give further reassurance regarding the robustness of interpretations provided here. The fact that we have not provided a review of measures that align with the outcome domains specified here might also be seen as a limitation. However, the purpose of this review was to articulate what to measure from a patient-centred perspective, not to identify and review the available measurement tools. This review is focused on adult burn survivors. It would be of value to conduct a similar review focused upon paediatric burn populations.

Conclusions

We propose that this outcome domain framework can be used as a basis for reflection on the outcome domains included in adult burn clinical research to ensure that they are patient-centred. In particular, we contend that sense of self should be considered a core outcome domain. Further work is required to reflect on how this and other domains can be assessed in a conceptually robust manner and whether domains are covered within existing measures, including measures of health-related QoL.

Abbreviations

LOS: length of stay; QoL: quality of life; SPIDER: sample, phenomenon of interest, design, evaluation, research type.

Supplementary data

Supplementary data is available at *Burns* & *Trauma* Journal online.

Availability of data and materials

The dataset underlying this review is available from the corresponding author upon reasonable request.

Authors' contributions

JM conceived the idea for the manuscript. JT and JM undertook the data analysis and interpretation with the input of all authors. NM, AB and FG gave initial input to the development of coding frameworks for the dataset. JM drafted the initial manuscript and all authors contributed to revisions prior to submission.

Conflicts of interest

None declared.

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