

BMJ Open Psychosocial and quality of life impact of scars in the surgical, traumatic and burn populations: a scoping review protocol

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ABSTRACT

Introduction Despite the fact that millions of scars affect individuals annually, little is known about their psychosocial impact and overall quality of life (QOL) on individuals. Scars from multiple aetiologies may cause psychiatric and emotional disturbances, can limit physical functioning and increase costs to the healthcare system. The purpose of this protocol is to describe the methodological considerations that will guide the completion of a scoping review that will summarise the extent, range and nature of psychosocial health outcomes and QOL of scars of all aetiologies.

Methods and analysis A modified Arksey and O'Malley (2005) framework will be completed, namely having ongoing consultation between experts from the beginning of the process, then (1) identifying the research question/s, (2) identifying the relevant studies from electronic databases and grey literature, with (3) study selection and (4) charting of data by two independent coders, and (5) collating, summarising and reporting data. Experts will include a health information specialist (TAW), scar expert (JSF), scoping review consultant (SCK), as well as at least two independent coders (NZ, AM).

Ethics and dissemination Ethics approval will not be sought for this scoping review. We plan to disseminate this research through publications, presentations and meetings with relevant stakeholders.

BACKGROUND

Millions of people develop scars from burn injuries, surgeries and traumatic events.¹⁻³ Scars are known to have wide ranging effects on individuals. For example, facial scars have been shown to impact psychosocial functioning causing increased anxiety and self-consciousness,⁴ traumatic scars can have the potential to impair social functioning and emotional well-being,⁵ and burn scars have been shown to decrease physical functioning.⁶ Recently, hypertrophic scars have been labelled the greatest unmet challenge both psychosocially and functionally to burn rehabilitation.⁷

Strengths and limitations of this study

- A scoping review examining the psychosocial and quality of life impact on individuals with scars has not been published before.
- A rigorous methodological framework will be completed with numerous quality checks throughout and every effort to obtain access to non-published work will be completed.
- A hybrid psychosocial and quality of life definition used with a new health outcome coding scheme will be used to examine the literature.
- Limitations include English articles, articles examining scars themselves (and not a surrogate marker of scars like total body surface area), and the scoping review process is time consuming

However, despite how common scars are, little is known about the psychosocial health outcomes that scars have on the individual. Scar-specific research has predominantly focused on clinical trials of scar modulation, diagnosis and improving our understanding of the physical symptoms of scars. Unfortunately, this research does not align with the WHO's definition of health that encompasses physical, mental and social well-being.⁸ Since scars are formed from inciting injuries (such as a burn/traumatic injury, surgery, inflammatory or oncologic disease) reviews regarding psychosocial impact and quality of life (QOL) of burn⁹⁻¹¹ and traumatic injuries¹²⁻¹⁶ do exist but a comprehensive review has not been conducted across all scar aetiologies. Furthermore, there has been an increased interest in psychosocial outcomes from the scientific communities themselves. For example, the 2016 American Burn Association's State of the Science conference recently called for scar research to extend to psychosocial impacts.¹⁷



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The exploration of psychosocial health outcomes and overall QOL of individuals with scars will be explored through a scoping review. Scoping reviews, as opposed to systematic reviews which synthesise quantitative findings, aim to investigate the extent (scar aetiology and patients affected), range (of patients and scar severity) and nature (what kind of psychosocial and QOL outcomes for this patient population) of research activity^{18 19} especially when a topic has either not been extensively reviewed, is complex, or heterogeneous.²⁰ In particular, scoping reviews map a given field of study, identify gaps in the current state of knowledge and aim to disseminate findings.¹⁸ To our knowledge, there is no such scoping review in this area. As a result, the findings and concepts generated from this scoping review will be able to inform clinicians about the effects of scarring on an individual across scar aetiologies given the conceptual generalisability and transferability²¹ of results ensured by the methodological rigour in the scoping review process.²¹

The protocol aims to comprehensively examine the effect of scars on individuals from a psychosocial health and QOL perspective. The term 'psychosocial' has been used broadly in research. As described by Martikainen *et al*,²² the term psychosocial has been used to describe causes and risk factors, mediating factors and contexts, and outcomes of various disease states and encompasses 'psychological distress', 'psychosocial well-being' and 'psychosocial health'. The term 'psychosocial outcome' has been further described and examined broadly in the context of emotional and social function,^{23 24} well-being, life satisfaction, self-esteem and overall QOL.²⁵ It has also been examined with particular disease states such as depression,²⁴⁻²⁷ anxiety,^{26 27} and emotions such as distress²⁶ in various clinical studies. Given the multiple definitions and lack of standardisation of psychosocial and QOL, we have created a hybrid psychosocial framework and will examine the scar through this lens. This framework is expanded on in stage 5.

The purpose of this protocol is to describe the methodological considerations that will guide the completion of a scoping review that will summarise the extent, range and nature of psychosocial health and QOL outcomes of scars of all aetiologies. Poor psychosocial outcomes have been associated with delayed recovery,²⁸ chronic disease progression and even mortality,²⁹⁻³¹ and the WHO has indicated that psychosocial risks have become a major health concern.^{32 33} We are interested in approaching the scar literature from a holistic viewpoint encompassing all types of scar aetiologies. This is an uncommon way of approaching the research question as the literature tends to be described using one scar aetiology. We are aiming to capture the full range of psychosocial outcomes from the perspective of patients with scars from different aetiologies (ie, scar from a major trauma vs a small scar from spilled tea vs acne or self-harm scars, and so on). We aim to identify the gaps in knowledge that may exist in terms of understanding how a scar may impact the psychosocial well-being of an individual. The outcome of the scoping

review will be to develop a comprehensive understanding of the current literature on the topic in order to improve clinical encounters, formulate new research questions and, ultimately, improve patient care.

METHODS AND ANALYSIS

A modified Arksey and O'Malley¹⁸ framework will be used in this scoping review. The original methodological framework of how to conduct a scoping review by Arksey and O'Malley includes six major stages: (1) identifying the research question/s; (2) identifying the relevant studies; (3) study selection; (4) charting the data; (5) collating, summarising and reporting data; and an optional stage, (6) ongoing consultation.¹⁸ This framework has been used to structure a number of scoping reviews in other areas of research.^{19 34 35} However, similar to Grant *et al*,³⁴ we feel that the optional stage 6, ongoing consultation, should be included as a first stage. Arksey and O'Malley¹⁸ endorse the use of consultation to help provide valuable insights, possibly additional resources, and alternative approaches to the research questions examined. In addition, Levac *et al*³⁶ suggest recommendations to refine the original framework with additional steps for each stage and specific considerations for scoping reviews in health research which we have adopted (refer to [table 1](#)).

Stage 1: ongoing consultation

As mentioned above, Arksey and O'Malley¹⁸ suggest ongoing consultation to occur at the end of the scoping review process, however as noted by Grant *et al*,³⁴ we believe ongoing consultation should be at the beginning. As stated by Levac *et al*,³⁶ ongoing consultation is an essential stage with an established purpose, which shapes the whole process of the scoping review. Three consultants have been selected: a specialist in scar modulation, a second with expertise in scoping reviews and a third health information specialist to ensure a thorough literature search of all pertinent published and non-published materials. We have specifically chosen these individuals based on their academic backgrounds and experience in their respective areas and will be involved in each stage moving forward.

Stage 2: identifying the research questions

Scoping reviews are expected to be comprehensive in nature and this goal is achieved with an appropriate research question. Arksey and O'Malley¹⁸ suggest keeping the research question broad but Levac *et al*³⁶ suggest having a broad research question with a clear scope of inquiry and defined outcome. Thus, following Levac *et al*'s³⁶ research question schema, our research questions are: how do scars impact patients from a psychosocial and QOL perspective? Second, of those studies included, what are the scar and patient variables examined? Specifically, variables that will be assessed are the location of the scar (visible or not, defined as any scar on the face, neck, hands and/or feet), scar aetiology, and patient ethnicity,

Table 1 Comparison of methods and overview of stages

Arksey and O'Malley ¹⁸ Stage	Arksey and O'Malley Details/stage	Levac <i>et al</i> ³⁶ Modifications to framework	Overview of phases
Ongoing consultation*	1. Optional stage completed at end.	1. Essential stage. 2. Establish purpose. 3. Articulate type of stakeholder to consult and how data will be collected, analysed, reported and integrated.	Stakeholders: 1. Scoping review expert (SCK). 2. Scar expert (JSF). 3. Health information specialist (TAW). 4. Two coders (AM, NZ).
Identifying research questions	1. Wide approach to scoping review research question including population, interventions or outcome.	1. Research question, consider: a. Concept. b. Target population. c. Health outcomes of interest. 2. Consider the intended outcome to help determine.	1. Research question: a. Scars. b. Individuals with scars. c. To determine the impact on psychosocial health and QOL. 2. Outcomes: a. Have a better understanding of the wide-ranging impact of scars on the individual in order to change clinical care, formulate research questions and improve patient care.
Identify relevant studies	Identify studies via: 1. Electronic databases. 2. Reference list. 3. Hand-searching of key journals. 4. Existing networks, relevant organisations, conferences. Consider: 1. Language. 2. Time span.	1. Research question and purpose guides decision-making. 2. Team.	Will identify studies in: a. Databases. b. Hand- search relevant reviews and papers. c. Examine websites from relevant associations and patient advocacy groups. Language restriction: English. Time span: no restriction.
Study selection	1. Post hoc inclusion and exclusion criteria after familiarisation of data. 2. Full-text articles that meet criteria.	1. Iterative process: constant refinements. 2. Inclusion and exclusion criteria discussed a priori, two coders will independently review articles. 3. Coders meet at beginning, midpoint and final stage. 4. Any disagreements resolved by third party.	1. Post hoc inclusion and exclusion criteria after familiarisation of data. 2. Iterative process: constant refinements. 3. Inclusion and exclusion criteria discussed a priori, two coders independently review articles (after a small pilot to ensure common understanding of criteria). 4. Coders meet at beginning, midpoint and final stage. 5. Any disagreements resolved by third party.
Charting the data	Charting: synthesising and interpreting qualitative data by sifting, charting and sorting materials based on key issues and themes.	1. Create a data extraction a priori. 2. Data extraction—iterative process. 3. Two independent authors extract data.	Charting, synthesising and interpreting qualitative data by sifting, charting and sorting materials based on key issues and themes by an iterative process of: 1. Creating a data extraction a priori with two independent authors to extract data.
Collating, summarising and reporting data	1. Present overview of all materials reviewed. 2. Summarise data extracted. 3. Identify research gaps.	1. Data analysis— quantitative and qualitative. 2. Report results. 3. Complete desired outcome. 4. Discuss implications for future research.	1. Present overview of data. 2. Summarise data extracted. 3. Report results. 4. Complete guideline. 5. Identify research gaps and discuss implications for future research.

*Ongoing consultation will occur throughout the scoping review process.³⁴
QOL, quality of life.

References: Arksey and O'Malley¹⁸; Levac *et al*³⁶.

gender and age (child vs adult). These variables were chosen with the guidance of the scar specialist (JSF) and through known debates in the literature regarding scar visibility,³⁷ aetiology,³⁸ and location,⁴ ethnicity,³⁹ gender⁴⁰ and age.⁴¹

By better understanding the psychosocial and QOL impact a scar may have on an individual, clinical care may be enhanced through the creation of guidelines, patient advocacy measures and improvement of clinical care. These variables were chosen with the guidance of the scar specialist and through known debates in the

literature regarding scar visibility,³⁷ aetiology,³⁸ and location,⁴ ethnicity,³⁹ gender⁴⁰ and age.⁴¹

Stage 3: identifying relevant studies

Identifying relevant studies will occur through three separate stages. First, through consultation with a health information specialist, we will conduct a key article search targeting relevant databases which will include MEDLINE, MEDLINE Epub Ahead of Print, In-Process & Other Non-Indexed Citations, EMBASE Classic, EMBASE and PsycINFO. Search terms will include a

combination of appropriate database subject headings (eg, MeSH, Emtree) and text words for the concepts of scars and psychological impact (self concept or self image or quality of life or satisfaction or sexuality or social adjustment or social desirability or social skills or social isolation or shame or stigma or anxiety or fear or happiness). A sample search strategy is found in online supplementary appendix 1. Second, pertinent journals selected by the scar expert (JSF) will be hand-searched (*Plastic and Reconstructive Surgery*, *Journal of Burn Care*, *Journal of Trauma*, *Burns*, *JAPRAS*, *Cleft Palate Journal*, *Body Image*) by two coders (AM, NZ). Finally, as per scoping review best practice guidelines, grey literature^{19 42} will be reviewed, specifically patient advocacy and association websites will be searched (by AM) for additional material regarding guidelines, reviews and clinical studies on the topic. Relevant journals and websites will be identified through consensus with the expert panel as well as through the preliminary database search. Authors will be contacted for any conference abstracts with minimal information or if full-text articles are not accessible. Finally, review articles will be hand-searched for relevant topics from key papers found in the article database search (AM, NZ). The searches will be limited to English with no time restriction.

Stage 4: study selection

Levac *et al*³⁶ suggest a team approach to study selection including both a transparent and replicable process with at least two coders selecting articles independently. Additionally, Reeves *et al*⁴³ propose a qualitative inter-rater reliability protocol for two or more independent coders with quality checks from a third party. Based on these suggestions, two coders will meet at the beginning, midpoint

and final stage with disagreements resolved by a third party. Inclusion and exclusion criteria will be completed after the literature review. A pilot sample of abstracts will be completed to ensure that all coders have a common understanding of the inclusion and exclusion criteria. A summary figure of all abstracts will be completed (figure 1).

Stage 5: charting the data

Similar to the previous stages, charting the data will include synthesising and interpreting the qualitative results in the included articles by sifting and sorting materials based on the key issues and themes.⁴⁴ Data extraction will be an iterative process and for quality assurance purposes, two independent coders will extract data from the literature into a preformed template on Excel. A coding manual will be created to ensure that the data extracted and coded are the same between two coders. Information extracted will consist of quantitative data regarding the articles and authors (such as number of authors, year of publication, study location), patient information (age, gender), scar information (scar aetiologies, location and visibility of scars), how scars were assessed/described and psychosocial and QOL impact on the individual. A hybrid definition encompassing elements of both psychosocial and generalised QOL will be used. First, we are specifically interested in examining psychosocial health from the framework created by Dr Lana Zinger,⁴⁵ which describes psychosocial health as consisting of emotional ('feeling'), mental ('thinking'), social (interactions with others) and spiritual (belief system, feeling of belonging) health. Further, emotions will be categorised into primary and secondary emotions as per Shaver *et al*.⁴⁶ In addition, the definition of QOL is provided by the WHO, specifically:

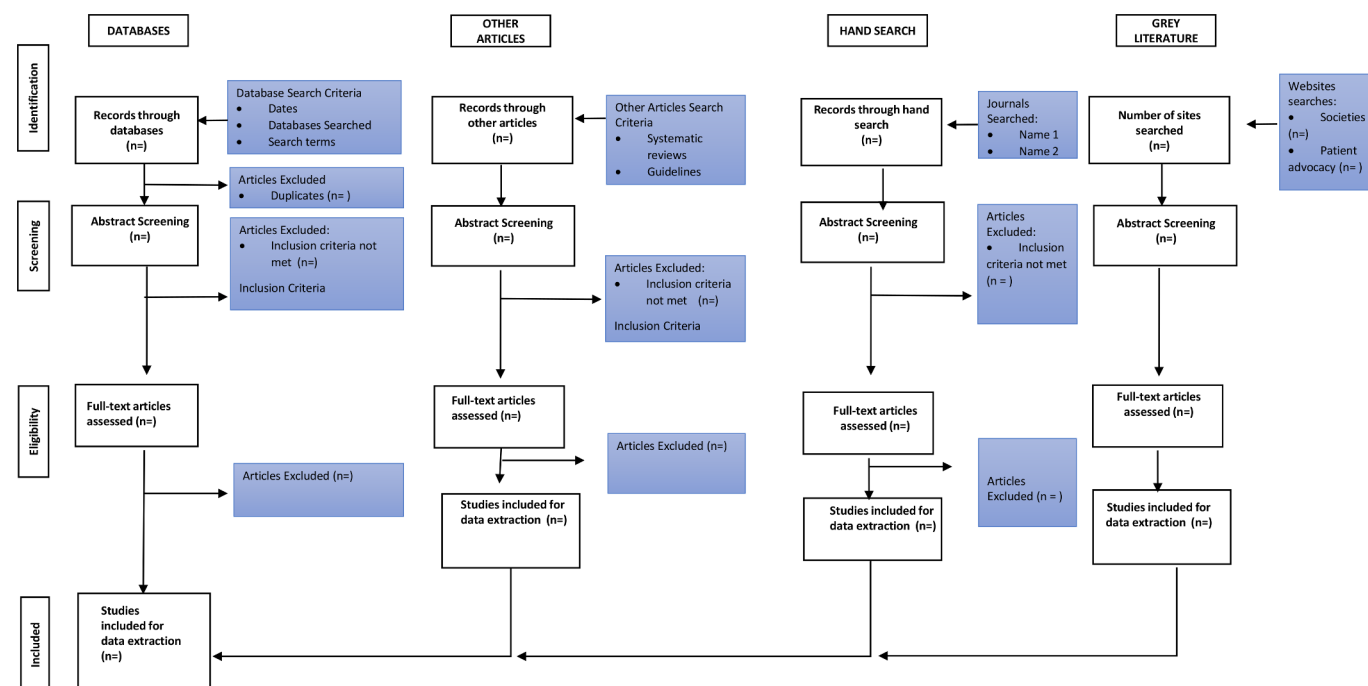


Figure 1 Flow chart.

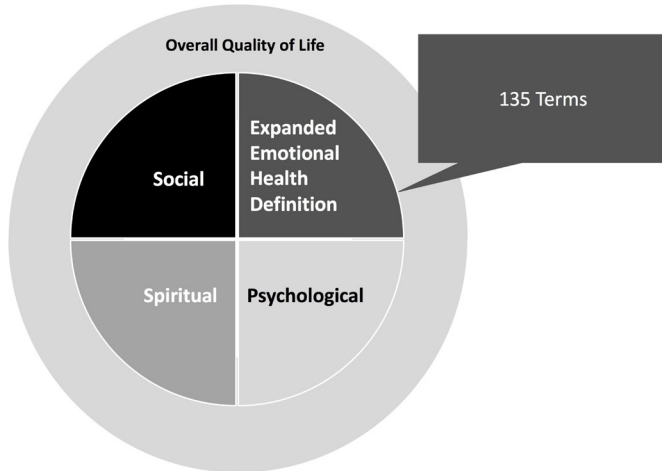


Figure 2 Framework (modified from Zinger [45]).

‘as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.’⁴⁷

Further, the WHO defines QOL as an indicator of well-being as related to healthcare.⁴⁷ These definitions will be used to define the general well-being not attributed to the psychosocial subcategories as defined above (see figure 2). As explained in the introduction, given the heterogeneity of psychosocial definitions,^{22–27} on careful consideration the team chose a simple and comprehensive definition that could be easily applied by both coders. To our knowledge, this is the first time a psychosocial framework has been used to inform the design and implementation of a scoping review coding structure within the literature on scoping review methodology.

Stage 6: collating, summarising and reporting data

Finally, we will present an overview of data from a quantitative and qualitative perspective. Quantitative analysis will be conducted through SAS software version 9.2 (SAS Inc, Cary NC) software and will consist of subgroup analysis of each variable (scar visibility, location, and aetiology and patient’s age and ethnicity). This analysis will be conducted to identify trends and gaps in knowledge as applied by the modified psychosocial framework. Content analysis will be used to guide the qualitative assessment.⁴⁴ We aim to report the results in a peer-reviewed journal article as well as in a conference setting. Further, we expect this work to generate a discussion and possibly lead to future research depending on the gaps in knowledge that are discovered. Finally, we will use these data to create guidelines, patient advocacy measures and, ultimately, improve patient care.

Patient and public involvement

The patients and the public were not involved in this protocol as the first step of the scoping review was to find

published literature in the area. Future studies will incorporate the patient’s perspective.

Ethics and dissemination

There is no need for a formal ethical review because no primary data will be collected. To the best of our knowledge, this study is the first to review the literature of the psychosocial and QOL impact of scars using a comprehensive scoping review methodology. We anticipate the study duration to occur from 1 January 2018 to 31 December 2018. We hope to compile the multitude of psychosocial effects that scars may have by investigating the extent, range and nature of research conducted within all scar patient populations (encompassing different ages and ethnicities as well as scar aetiologies) through this scoping review. The findings from the review will be submitted to relevant journals and conferences such as the American Burn Association and Canadian and American Plastic Surgery conferences. Finally, we aim to share our results with key stakeholders to help change clinical practice. By better understanding the psychosocial health and QOL impact of scars on the individual, we can formulate new research questions through the identification of research gaps, creation of treatment guidelines and, ultimately, improvement of patient care.

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