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## **BMJ Open**

# The psychosocial and quality of life impact of scars in the surgical, traumatic, and burn populations: A Scoping Review Protocol

Journal:	BMJ Open
Manuscript ID	bmjopen-2017-021289
Article Type:	Protocol
Date Submitted by the Author:	20-Dec-2017
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Keywords:	scar, PLASTIC & RECONSTRUCTIVE SURGERY, psychosocial outcomes, quality of life, burn, SURGERY

#### SCHOLARONE<sup>™</sup> Manuscripts

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Key Words: cicatrix; quality of life; review; surgery, plastic; burns

Word Count: 2427

Funding: No funding to report.

Competing interests: There are no competing interests.

Contributor Statement:

All authors have made substantive intellectual contributions. NZ, SCK, JSF, TAW were involved in conceptualizing this review. NZ, SCK, JSF were involved in writing this protocol. DJ, JZ, AM, TAW commented critically on several drafts of this manuscript.

#### 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 etiologies 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 summarize the extent, range, and nature of psychosocial health outcomes and QOL of scars of all etiologies. 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, summarizing, and reporting data. Experts will include a health information specialist(TA-W), scar expert(JF), scoping review consultant(SK), as well as at least two independent coders(NZ, AM). **Ethics and Dissemination:** Ethics approval was not sought for this scoping review. We plan to disseminate this research through publications, presentations, and meetings with relevant stakeholders. 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

- Work will identify gaps in research and help develop guidelines to aid clinical practice
- 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 was used to examine the literature
- Limitations include English articles, articles examining scars themselves (and not a surrogate marker of scars like TBSA), and the scoping review process is time-consuming

Millions of people develop scars from burn injuries, surgeries, and traumatic events.<sup>1-3</sup> 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 selfconsciousness<sup>4</sup>, traumatic scars can have the potential to impair social functioning and emotional well-being,<sup>5</sup> and burn scar have been shown to decrease physical functioning<sup>6</sup>. Recently, hypertrophic scars have been labelled the greatest unmet challenge both psychosocially and functionally to burn rehabilitation<sup>7</sup>.

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 World Health Organization's definition of health that encompasses not only physical but also mental and social well-being<sup>8</sup>. 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 burn<sup>10,11</sup> and traumatic injuries<sup>12-16</sup> do exist but a comprehensive review has not been conducted across all scar etiologies. 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<sup>17</sup>.

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, aim to investigate the extent (scar etiology 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<sup>18,19</sup> especially when a topic has either not been extensively reviewed, is complex, or heterogeneous<sup>20</sup>. In particular, scoping reviews map a given field of study, identify gaps in the current state of knowledge, and aim to disseminate findings<sup>18</sup>. 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 etiologies given the conceptual generalizability and transferability<sup>21</sup> of results ensured by the methodological rigor in the scoping review process<sup>21</sup>.

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 (2002)<sup>22</sup> 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<sup>23,24</sup>, well-being, life satisfaction, self-esteem, and overall QOL<sup>25</sup>. It has also been examined with particular disease states such as depression<sup>24-27</sup>, anxiety<sup>26,27</sup>, and emotions such as distress<sup>26</sup> in various clinical studies. Given the multiple definitions and lack of standardization 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 summarize the extent, range, and nature of psychosocial health and QOL outcomes of scars of all etiologies. Poor psychosocial outcomes have been associated with delayed recovery<sup>28</sup>, chronic disease progression and even mortality<sup>29-31</sup> and the World Health Organization has indicated that psychosocial risks have become a major health concern<sup>32,33</sup>. Thus we aim to identify the gaps in knowledge that may exist in terms of understanding how a scar may impact the psychosocial wellbeing 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'Malley<sup>18</sup> framework was used in this scoping review. The original methodological framework of how to conduct a scoping review by Arksey and O'Malley (2005) includes six major stages: (1) identifying the research question/s, (2) identifying the relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing, and reporting data, and an optional stage, (6) ongoing consultation<sup>18</sup>. This framework has been used to structure a number of scoping reviews in other areas of research<sup>19,34,35</sup>. However, similar to Grant et al (2015)<sup>34</sup>, we feel that the optional stage 6, ongoing consultation, should be included as a first stage. Arksey and O'Malley (2005)<sup>18</sup> 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 (2010)<sup>36</sup> 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. Please refer to Table 1: Comparison of Methods and Overview of Stages.

Arksey and O'Malley Stage <sup>18</sup>	Arksey and O'Malley Details/Stage	Levac et al <sup>36</sup> Modifications to Framework	Overview of Phases
Ongoing Consultation*	1) Optional stage completed at end	<ol> <li>1) Essential stage</li> <li>2) Establish purpose</li> <li>3) Articulate type of stakeholder to consult &amp; how data will be collected, analyzed, reported, and integrated</li> </ol>	Stakeholders: 1) Scoping review expert (SK) 2) Scar expert (JF) 3) Health information specialist (TA-W) 4) Two coders (AM, NZ)
Identifying Research Questions	1) Wide approach to scoping review research question including population, interventions or outcome	<ol> <li>Research Question, consider:         <ul> <li>a) concept</li> <li>b) target</li> <li>population</li> <li>c) health</li> </ul> </li> </ol>	<ol> <li>1) Research</li> <li>Question:</li> <li>a) scars</li> <li>b) individuals with</li> <li>scars</li> <li>c) to determine the</li> </ol>

Table 1: Comparison of Methods and Overview of Stages.

		outcomes of interest 2) Consider the intended outcome to help determine	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 organizations, conferences Consider: 1) language 2) time span	<ol> <li>Research question and purpose guides decision-making</li> <li>Team</li> </ol>	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	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Full text articles that meet criteria</li> </ol>	<ol> <li>1) Iterative process: constant refinements</li> <li>2) Inclusion &amp; exclusion criteria discussed a priori, 2 coders will independently review articles</li> <li>3) Coders meet at beginning, midpoint, and final stage</li> <li>4) Any disagreements resolved by third party</li> </ol>	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Iterative process: constant refinements</li> <li>Inclusion &amp; exclusion criteria discussed a priori, 2 coders independently review articles (after a small pilot to ensure common</li> </ol>

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			understanding of criteria) 4) Coders meet at beginning, midpoint, and final stage 5) Any disagreements resolved by third party
Charting the Data	Charting: synthesizing and interpreting qualitative data by sifting, charting, sorting material based on key issues and themes	<ol> <li>Create a data extraction a priori</li> <li>Data extraction – iterative process</li> <li>2 independent authors extract data</li> </ol>	Charting, synthesizing, interpreting qualitative data by sifting, charting, sorting material based on key issues and themes by an iterative process of: 1) Creating a data extraction a priori with 2 independent authors extract data
Collating, Summarizing, and Reporting Data	<ol> <li>Present overview of all material reviewed</li> <li>Summarize data extracted</li> <li>Identify research gaps</li> </ol>	<ol> <li>Data analysis – quantitative and qualitative</li> <li>Report results</li> <li>Complete desired outcome</li> <li>Discuss implications for future research</li> </ol>	<ol> <li>Present overview of data</li> <li>Summarize data extracted</li> <li>Report results</li> <li>Complete guideline</li> <li>Identify research gaps and discuss implications for future research</li> </ol>

\*Ongoing consultation will occur throughout the scoping review process<sup>3</sup> References:

Arksey H & O'Malley L. Scoping Studies: Towards A Methodological Framework. *Int J Soc Res Methodol* 2005;8(1):19-32.

Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci.* 2010;5:69.

#### 1) Stage 1: Ongoing Consultation

As mentioned above, Arksey and O'Malley (2005)<sup>18</sup> suggest ongoing consultation to occur at the end of the scoping review process however as noted by Grant et al (2015)<sup>34</sup>, we believe

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ongoing consultation should be at the beginning. As stated by Levac et al (2010)<sup>36</sup>, 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 material. 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.

#### 2) 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'Malley<sup>18</sup> suggest keeping the research question broad but Levac et al (2010)<sup>36</sup> suggest having a broad research question with a clear scope of inquiry and defined outcome. Thus, following Levac et al (2010)<sup>36</sup> our research questions will allow us to:

- Determine the extent (specifically, scar etiology and patients affected), range (of patients and scar severity), and nature (of outcomes) specifically, how scars may impact patients from a psychosocial and QOL perspective
  - a) Have a broader understanding of how location of the scar (visible or not), scar etiology, and patient ethnicity, gender and age (child versus adult) may impact the individual differently
- 2) 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 improve clinical care

These variables were chosen with the guidance of the scar specialist and through known debates in the literature regarding scar visibility<sup>37</sup>, etiology<sup>38</sup>, and location<sup>4</sup>, ethnicity<sup>39</sup>, gender<sup>40</sup>, and age<sup>41</sup>.

#### 3) 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, EMBASE Classic, EMBASE, and PsycINFO. Second, pertinent journals selected by the scar expert (JF) will be hand-searched (Plastic and Reconstructive Surgery, Journal of Burn Care, Journal of Trauma) by two coders (AM, NZ). Finally, as per scoping review best practice guidelines, grey literature<sup>19,42</sup> 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.

#### 4) Stage 4: Study Selection

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Levac et al (2010)<sup>36</sup> 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 (2014)<sup>43</sup> proposes 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: Flowchart.

#### 5) Stage 5: Charting the Data

Similar to the previous stages, charting the data will include synthesizing and interpreting the qualitative results in the included articles by sifting and sorting material based on the key issues and themes<sup>44</sup>. Data extraction will be an iterative process and for quality assurance purposes, two independent coders will extract data from the literature into a pre-formed 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 etiologies, 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 generalized QOL will be utilized. First, we are specifically interested in examining psychosocial health from the framework created by Dr. Lana Zinger (2011)<sup>45</sup> 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 categorized into primary and secondary emotions as per Shaver et al (2001)<sup>46</sup>. In addition, the definition of QOL is "a broad construct contributed to by many aspects of life...and is influenced by one's personal values"<sup>47</sup>, and was used to define the general well-being not attributed to the psychosocial subcategories as defined above. Please see Figure 2: Framework. As explained in the introduction, given the heterogeneity of psychosocial definitions<sup>22-27</sup>, upon careful consideration the team chose a simple and comprehensive definition that could be easily applied by both coders. Finally, each coded result will then be rated to determine if the health outcome is positive, negative, or neutral from the patient's perspective. This analysis will improve our understanding of the type of psychosocial outcomes that individuals with scars may have. 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.

#### 6) Stage 6: Collating, Summarizing, and Reporting Data

Finally, we will present an overview of data from a quantitative and qualitative perspective. Quantitative analysis will be conducted through SAS<sup>®</sup> (University Edition, SAS Institute Inc., Cary, NC, USA) software and will consist of sub-group analysis of each variable (scar visibility, location, and etiology 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<sup>48</sup>. 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 this data to create guidelines, patient advocacy measures, and ultimately, improve patient care.

#### **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 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 etiologies) 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, create treatment guidelines, and ultimately, improve patient care.

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#### Figure Legend

Figure 1: Flowchart <

Figure 2: Framework

Modified from:

Zinger, L. "Health The Basics, Green Edition: Chapter 2: Psychosocial Health." Los Angelese Harbor College. Accessed from:

https://www.lahc.edu/classes/pe/health/health11media/Health\_11\_Chapter\_2\_ Psychosocial-PDF.pdf

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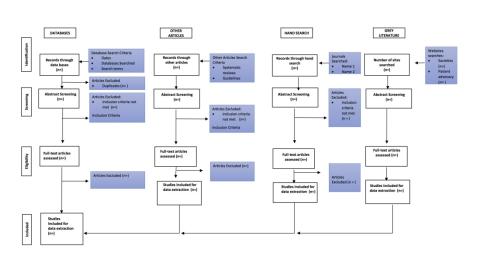
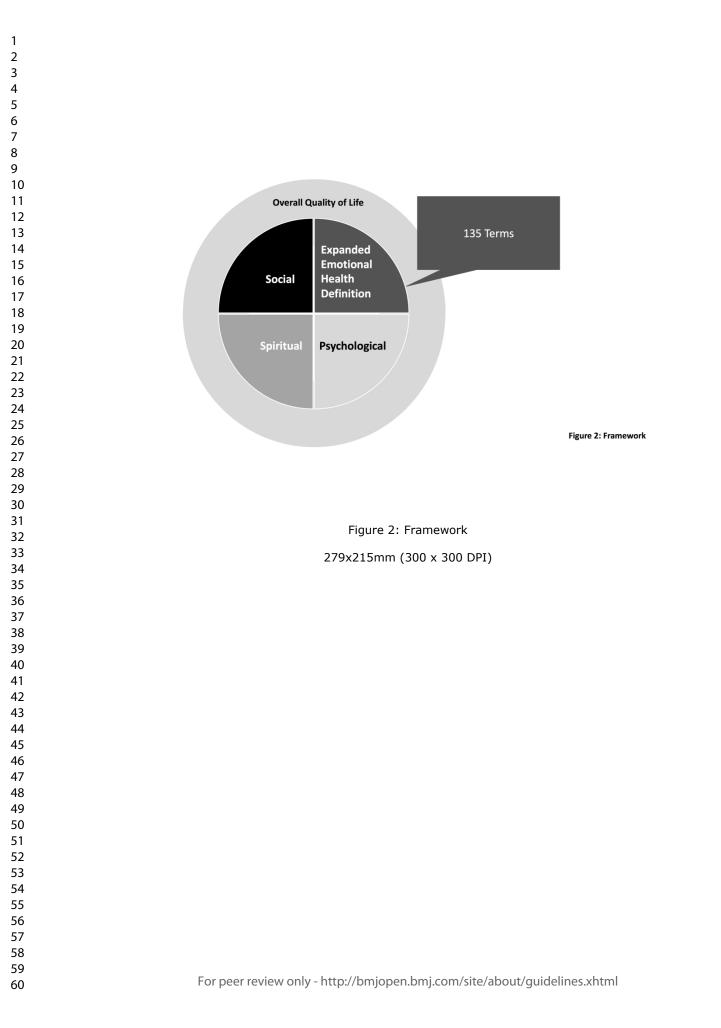


Figure 1: Flowchart



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### **BMJ Open**

# The psychosocial and quality of life impact of scars in the surgical, traumatic, and burn populations: A Scoping Review Protocol

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Journal:	BMJ Open
Manuscript ID	bmjopen-2017-021289.R1
Article Type:	Protocol
Date Submitted by the Author:	24-Apr-2018
Complete List of Authors:	Ziolkowski, Natalia; University of Toronto, Surgery; Kitto, Simon; University of Ottawa, Department of Innovation in Medical Education, and the Office of Continuing Professional Development, Faculty of Medicine; University of Toronto, Department of Surgery Jeong, Dahn; University of Ottawa, Department of Innovation in Medical Education, and the Office of Continuing Professional Development, Faculty of Medicine Zuccaro, Jennifer; The Hospital for Sick Children, Division of Plastic and Reconstructive Surgery Adams-Webber, Thomasin; The Hospital for Sick Children, Hospital Library and Archives Miroshynchenko, Anna; McMaster University, Department of Life Sciences, Faculty of Science Fish, Joel; The Hospital for Sick Children, Division of Plastic and Reconstructive Surgery; University of Toronto, Department of Surgery
<b>Primary Subject Heading</b> :	Surgery
Secondary Subject Heading:	Patient-centred medicine, Rehabilitation medicine, Health services research
Keywords:	scar, PLASTIC & RECONSTRUCTIVE SURGERY, psychosocial outcomes, quality of life, burn, SURGERY

SCHOLARONE<sup>™</sup> Manuscripts

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Key Words: cicatrix; quality of life; review; surgery, plastic; burns

Word Count: 2427

Funding: No funding to report.

Competing interests: There are no competing interests.

Contributor Statement:

All authors have made substantive intellectual contributions. NZ, SCK, JSF, TAW were involved in conceptualizing this review. NZ, SCK, JSF were involved in writing this protocol. DJ, JZ, AM, TAW commented critically on several drafts of this manuscript.

#### 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 etiologies 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 summarize the extent, range, and nature of psychosocial health outcomes and QOL of scars of all etiologies. 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)

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, summarizing, and reporting data. Experts will include a health information specialist (TA-W), scar expert(JF), scoping review consultant(SK), 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.

#### 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
- Work will identify gaps in research and help develop guidelines to aid clinical practice
- 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 QOL 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 TBSA), and the scoping review process is time-consuming

#### BACKGROUND

Millions of people develop scars from burn injuries, surgeries, and traumatic events.<sup>1-3</sup> 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 selfconsciousness<sup>4</sup>, traumatic scars can have the potential to impair social functioning and emotional well-being,<sup>5</sup> and burn scar have been shown to decrease physical functioning<sup>6</sup>. Recently, hypertrophic scars have been labelled the greatest unmet challenge both psychosocially and functionally to burn rehabilitation<sup>7</sup>.

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 World Health Organization's definition of health that encompasses not only physical but also mental and social well-being<sup>8</sup>. 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 burn<sup>9-11</sup> and traumatic injuries<sup>12-16</sup> do exist but a comprehensive review has not been conducted across all scar etiologies. 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<sup>17</sup>.

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 synthesize quantitative findings, aim to investigate the extent (scar etiology 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<sup>18,19</sup> especially when a topic has either not been extensively reviewed, is complex, or heterogeneous<sup>20</sup>. In particular, scoping reviews map a given field of study, identify gaps in the current state of knowledge, and aim to disseminate findings<sup>18</sup>. 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 etiologies given the conceptual generalizability and transferability<sup>21</sup> of results ensured by the methodological rigor in the scoping review process<sup>21</sup>.

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 (2002)<sup>22</sup> 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<sup>23,24</sup>, well-being, life satisfaction, self-esteem, and overall QOL<sup>25</sup>. It has also been examined with particular disease states such as depression<sup>24-27</sup>, anxiety<sup>26,27</sup>, and emotions such as distress<sup>26</sup> in various clinical studies. Given the multiple definitions and lack of standardization 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 summarize the extent, range, and nature of psychosocial health and QOL outcomes of scars of all etiologies. Poor psychosocial outcomes have been associated with delayed recovery<sup>28</sup>, chronic disease progression and even mortality<sup>29-31</sup> and the World Health Organization has indicated that psychosocial risks have become a major health concern<sup>32,33</sup>. We are interested in approaching the scar literature from a holistic viewpoint encompassing all types of scar etiologies. This is an uncommon way of approaching the research question as the literature tends to be described using one scar etiology. We are aiming to capture the full range of psychosocial outcomes from the perspective of patients with scars from different etiologies (i.e. scar from a major trauma, vs. a small scar from spilled tea vs. acne or self-harm scars etc). We aim to identify the gaps in knowledge that may exist in terms of understanding how a scar may impact the psychosocial wellbeing 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'Malley<sup>18</sup> framework will be used in this scoping review. The original methodological framework of how to conduct a scoping review by Arksey and O'Malley (2005) includes six major stages: (1) identifying the research question/s, (2) identifying the relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing, and reporting data, and an optional stage, (6) ongoing consultation<sup>18</sup>. This framework has been used to structure a number of scoping reviews in other areas of research<sup>19,34,35</sup>. However, similar to Grant et al (2015)<sup>34</sup>, we feel that the optional stage 6, ongoing consultation, should be included as a first stage. Arksey and O'Malley (2005)<sup>18</sup> 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 (2010)<sup>36</sup> 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. Please refer to Table 1: Comparison of Methods and Overview of Stages.

Table 1: Comparison of Methods and Overview of Stages.

Arksey and O'Malley Stage <sup>18</sup>	Arksey and O'Malley Details/Stage	Levac et al <sup>36</sup> Modifications to Framework	Overview of Phases
Ongoing	1) Optional stage	1) Essential stage	Stakeholders:
Consultation*	completed at end	<ol> <li>2) Establish purpose</li> <li>3) Articulate type of</li> <li>stakeholder to</li> <li>consult &amp; how data</li> <li>will be collected,</li> <li>analyzed, reported,</li> <li>and integrated</li> </ol>	<ol> <li>Scoping review expert (SK)</li> <li>Scar expert (JF)</li> <li>Health information specialist (TA-W)</li> <li>Two coders (AM, NZ)</li> </ol>

Identifying Research Questions	1) Wide approach to scoping review research question including population, interventions or outcome	<ol> <li>Research Question, consider:         <ul> <li>a) concept</li> <li>b) target</li> <li>population</li> <li>c) health</li> <li>outcomes of</li> <li>interest</li> </ul> </li> <li>Consider the</li> <li>intended outcome to</li> <li>help determine</li> </ol>	<ol> <li>Research Question:         <ul> <li>a) scars</li> <li>b) individuals with scars</li> <li>c) to determine the impact on psychosocial health and QOL</li> <li>2) Outcomes:                 <ul> <li>a) have a better</li> <li>understanding of</li> <li>the wide ranging</li> <li>impact of scars on</li> <li>the individual in</li> <li>order to change</li> <li>clinical care,</li> <li>formulate research</li> <li>questions, and</li> <li>improve patient care</li> </ul> </li> </ul> </li> </ol>
Identify Relevant Studies	Identify studies via: 1) electronic databases 2) reference list 3) hand-searching of key journals 4) existing networks, relevant organizations, conferences Consider: 1) language 2) time span	<ol> <li>Research question and purpose guides decision-making</li> <li>Team</li> </ol>	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	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Full text articles that meet criteria</li> </ol>	<ol> <li>1) Iterative process: constant refinements</li> <li>2) Inclusion &amp; exclusion criteria discussed a priori, 2 coders will independently review articles</li> </ol>	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Iterative process: constant refinement</li> <li>Inclusion &amp; exclusion criteria</li> </ol>

		<ul> <li>3) Coders meet at beginning, midpoint, and final stage</li> <li>4) Any disagreements resolved by third party</li> </ul>	discussed a priori, 2 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: synthesizing and interpreting qualitative data by sifting, charting, sorting material based on key issues and themes	<ol> <li>Create a data extraction a priori</li> <li>Data extraction – iterative process</li> <li>2 independent authors extract data</li> </ol>	Charting, synthesizing, interpreting qualitative data by sifting, charting, sorting material based on key issues and themes by an iterative process of: 1) Creating a data extraction a priori with 2 independent authors extract data
Collating, Summarizing, and Reporting Data	<ol> <li>Present overview of all material reviewed</li> <li>Summarize data extracted</li> <li>Identify research gaps</li> </ol>	<ol> <li>1) Data analysis – quantitative and qualitative</li> <li>2) Report results</li> <li>3) Complete desired outcome</li> <li>4) Discuss implications for future research</li> </ol>	<ol> <li>Present overview of data</li> <li>Summarize data extracted</li> <li>Report results</li> <li>Complete guideline</li> <li>Identify research gaps and discuss implications for future research</li> </ol>

Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci.

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2010;5:69.

#### 1) Stage 1: Ongoing Consultation

As mentioned above, Arksey and O'Malley (2005)<sup>18</sup> suggest ongoing consultation to occur at the end of the scoping review process however as noted by Grant et al (2015)<sup>34</sup>, we believe ongoing consultation should be at the beginning. As stated by Levac et al (2010)<sup>36</sup>, 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 material. 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.

#### 2) 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'Malley<sup>18</sup> suggest keeping the research question broad but Levac et al (2010)<sup>36</sup> suggest having a broad research question with a clear scope of inquiry and defined outcome. Thus, following Levac et al (2010)<sup>36</sup> our research questions are:

- What is the extent (specifically, scar etiology and patients affected), range (least to most of each scar and patient characteristic studied, for example youngest to oldest patient) of patients and scar severity), and nature (of outcomes) specifically, how scars may impact patients from a psychosocial and QOL perspective
  - a) How does the location of the scar (visible or not, defined as any scar on the face, beck, hands, and/or feet), scar etiology, and patient ethnicity, gender and age (child versus adult) impact the individual from a psychosocial perspective?

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 improve clinical care. These variables were chosen with the guidance of the scar specialist and through known debates in the literature regarding scar visibility<sup>37</sup>, etiology<sup>38</sup>, and location<sup>4</sup>, ethnicity<sup>39</sup>, gender<sup>40</sup>, and age<sup>41</sup>.

#### 3) 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 (e.g. 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). Second, pertinent journals selected by the scar expert (JF) 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<sup>19,42</sup>
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.

#### 4) Stage 4: Study Selection

Levac et al (2010)<sup>36</sup> 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 (2014)<sup>43</sup> proposes 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: Flowchart.

#### 5) Stage 5: Charting the Data

Similar to the previous stages, charting the data will include synthesizing and interpreting the qualitative results in the included articles by sifting and sorting material based on the key issues and themes<sup>44</sup>. Data extraction will be an iterative process and for quality assurance purposes, two independent coders will extract data from the literature into a pre-formed 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 etiologies, 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 generalized QOL will be utilized. First, we are specifically interested in examining psychosocial health from the framework created by Dr. Lana Zinger (2011)<sup>45</sup> 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 categorized into primary and secondary emotions as per Shaver et al (2001)<sup>46</sup>. In addition, the definition of QOL is "a broad construct contributed to by many aspects of life...and is influenced by one's personal values"<sup>47</sup>. Further, the World Health Organization defines quality of life as an indicator of well-being as related to health care.<sup>48</sup> These definitions will be used to define the general well-being not attributed to the psychosocial subcategories as defined above. Please see Figure 2: Framework. As explained in the introduction, given the heterogeneity of psychosocial definitions<sup>22-27</sup>, upon 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

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within the literature on scoping review methodology.

#### 6) Stage 6: Collating, Summarizing, and Reporting Data

Finally, we will present an overview of data from a quantitative and qualitative perspective. Quantitative analysis will be conducted through SAS® (University Edition, SAS Institute Inc., Cary, NC, USA) software and will consist of sub-group analysis of each variable (scar visibility, location, and etiology 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<sup>44</sup>. 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 this data to create guidelines, patient advocacy measures, and ultimately, improve patient care.

#### **Patient and Public Involvement**

Patients and the Public were not involved in this protocol.

#### 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 January 1, 2018 to December 31, 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 etiologies) 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, create treatment guidelines, and ultimately, improve patient care.

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https://www.lahc.edu/classes/pe/health/health11media/Health\_11\_Chapter\_2\_ Psychosocial-PDF.pdf



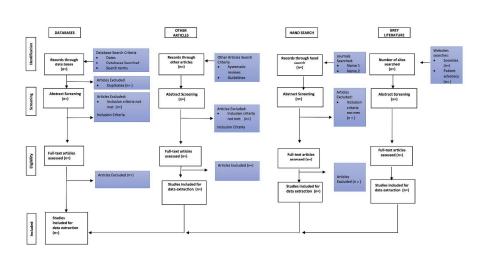
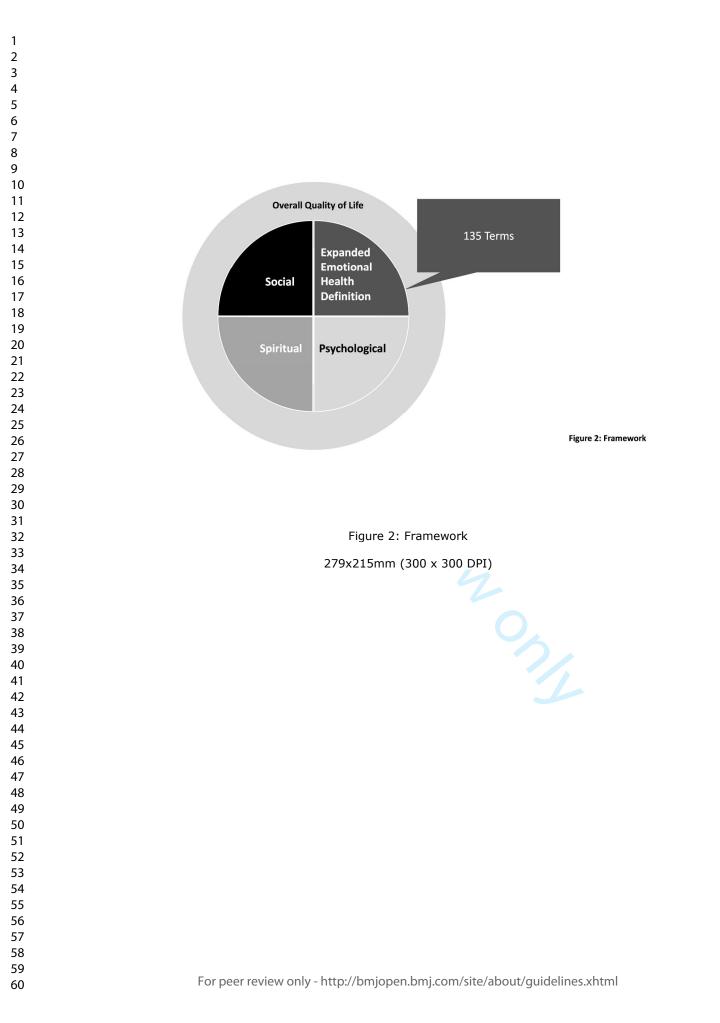


Figure 1: Flowchart



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## **BMJ Open**

# The psychosocial and quality of life impact of scars in the surgical, traumatic, and burn populations: A Scoping Review Protocol

Journal:	BMJ Open
Manuscript ID	bmjopen-2017-021289.R2
Article Type:	Protocol
Date Submitted by the Author:	13-Aug-2018
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<b>Primary Subject Heading</b> :	Surgery
Secondary Subject Heading:	Patient-centred medicine, Rehabilitation medicine, Health services research
Keywords:	scar, PLASTIC & RECONSTRUCTIVE SURGERY, psychosocial outcomes, quality of life, burn, SURGERY



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Key Words: cicatrix; quality of life; review; surgery, plastic; burns

Word Count: 2427

Funding: No funding to report.

Competing interests: There are no competing interests.

Contributor Statement:

All authors have made substantive intellectual contributions. NZ, SCK, JSF, TAW were involved in conceptualizing this review. NZ, SCK, JSF were involved in writing this protocol. DJ, JZ, AM, TAW commented critically on several drafts of this manuscript.

## 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 etiologies 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 summarize the extent, range, and nature of psychosocial health outcomes and QOL of scars of all etiologies. 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, summarizing, and reporting data. Experts will include a health information specialist (TA-W), scar expert(JF), scoping review consultant(SK), 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.

### 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 TBSA), and the scoping review process is time-consuming

 Millions of people develop scars from burn injuries, surgeries, and traumatic events.<sup>1-3</sup> 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 selfconsciousness<sup>4</sup>, traumatic scars can have the potential to impair social functioning and emotional well-being,<sup>5</sup> and burn scar have been shown to decrease physical functioning<sup>6</sup>. Recently, hypertrophic scars have been labelled the greatest unmet challenge both psychosocially and functionally to burn rehabilitation<sup>7</sup>.

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 World Health Organization's definition of health that encompasses not only physical but also mental and social well-being<sup>8</sup>. 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 burn<sup>9-11</sup> and traumatic injuries<sup>12-16</sup> do exist but a comprehensive review has not been conducted across all scar etiologies. 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<sup>17</sup>.

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 synthesize quantitative findings, aim to investigate the extent (scar etiology 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<sup>18,19</sup> especially when a topic has either not been extensively reviewed, is complex, or heterogeneous<sup>20</sup>. In particular, scoping reviews map a given field of study, identify gaps in the current state of knowledge, and aim to disseminate findings<sup>18</sup>. 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 etiologies given the conceptual generalizability and transferability<sup>21</sup> of results ensured by the methodological rigor in the scoping review process<sup>21</sup>.

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 (2002)<sup>22</sup> 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<sup>23,24</sup>, well-being, life satisfaction, self-esteem, and overall QOL<sup>25</sup>. It has also been examined with particular disease states such as depression<sup>24-27</sup>, anxiety<sup>26,27</sup>, and emotions such as distress<sup>26</sup> in various clinical studies. Given the multiple definitions and lack of standardization 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.

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The purpose of this protocol is to describe the methodological considerations that will guide the completion of a scoping review that will summarize the extent, range, and nature of psychosocial health and QOL outcomes of scars of all etiologies. Poor psychosocial outcomes have been associated with delayed recovery<sup>28</sup>, chronic disease progression and even mortality<sup>29-31</sup> and the World Health Organization has indicated that psychosocial risks have become a major health concern<sup>32,33</sup>. We are interested in approaching the scar literature from a holistic viewpoint encompassing all types of scar etiologies. This is an uncommon way of approaching the research question as the literature tends to be described using one scar etiology. We are aiming to capture the full range of psychosocial outcomes from the perspective of patients with scars from different etiologies (i.e. scar from a major trauma, vs. a small scar from spilled tea vs. acne or self-harm scars etc). We aim to identify the gaps in knowledge that may exist in terms of understanding how a scar may impact the psychosocial wellbeing 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'Malley<sup>18</sup> framework will be used in this scoping review. The original methodological framework of how to conduct a scoping review by Arksey and O'Malley (2005) includes six major stages: (1) identifying the research question/s, (2) identifying the relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing, and reporting data, and an optional stage, (6) ongoing consultation<sup>18</sup>. This framework has been used to structure a number of scoping reviews in other areas of research<sup>19,34,35</sup>. However, similar to Grant et al (2015)<sup>34</sup>, we feel that the optional stage 6, ongoing consultation, should be included as a first stage. Arksey and O'Malley (2005)<sup>18</sup> 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 (2010)<sup>36</sup> 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. Please refer to Table 1: Comparison of Methods and Overview of Stages.

Table 1: Comparison of Methods and Overview of Stages.

Arksey and O'Malley Stage <sup>18</sup>	Arksey and O'Malley Details/Stage	Levac et al <sup>36</sup> Modifications to Framework	Overview of Phases
Ongoing	1) Optional stage	1) Essential stage	Stakeholders:
Consultation*	completed at end	2) Establish purpose	1) Scoping review
		3) Articulate type of	expert (SK)
		stakeholder to	2) Scar expert (JF)
		consult & how data	3) Health
		will be collected,	information
		analyzed, reported,	specialist (TA-W)
		and integrated	4) Two coders (AM,
		_	NZ)

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Identifying Research Questions	1) Wide approach to scoping review research question including population, interventions or outcome	<ol> <li>Research Question, consider:         <ul> <li>a) concept</li> <li>b) target</li> <li>population</li> <li>c) health</li> <li>outcomes of</li> <li>interest</li> </ul> </li> <li>2) Consider the</li> <li>intended outcome to</li> </ol>	<ol> <li>Research Question:         <ul> <li>a) scars</li> <li>b) individuals with</li> <li>scars</li> <li>c) to determine the</li> <li>impact on</li> <li>psychosocial health</li> <li>and QOL</li> <li>2) Outcomes:</li> </ul> </li> </ol>
		help determine	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 organizations, conferences Consider: 1) language 2) time span	<ol> <li>1) Research question and purpose guides decision-making</li> <li>2) Team</li> </ol>	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	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Full text articles that meet criteria</li> </ol>	<ol> <li>1) Iterative process: constant refinements</li> <li>2) Inclusion &amp; exclusion criteria discussed a priori, 2 coders will independently review articles</li> <li>3) Coders meet at</li> </ol>	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Iterative process: constant refinements</li> <li>Inclusion &amp; exclusion criteria discussed a priori, 2</li> </ol>

		beginning, midpoint, and final stage 4) Any disagreements resolved by third party	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	Charting: synthesizing	1) Create a data	Charting,
Data	and interpreting	extraction a priori	synthesizing,
	qualitative data by	2) Data extraction –	interpreting
	sifting, charting,	iterative process	qualitative data by
	sorting material based	3) 2 independent	sifting, charting,
	on key issues and	authors extract data	sorting material
	themes		based on key issues
			and themes by an
			iterative process of:
			1) Creating a data
			extraction a priori
			with 2 independent
			authors extract data
Collating,	1) Present overview of	1) Data analysis –	1) Present overview
Summarizing,	all material reviewed	quantitative and	of data
and Reporting	2) Summarize data	qualitative	2) Summarize data
Data	extracted	2) Report results	extracted
	3) Identify research	<ol> <li>Complete desired</li> </ol>	<ol><li>Report results</li></ol>
	gaps	outcome	4) Complete
		4) Discuss	guideline
		implications for	5) Identify research
		future research	gaps and discuss
			implications for
			future research

Arksey H & O'Malley L. Scoping Studies: Towards A Methodological Framework. *Int J Soc Res Methodol* 2005;8(1):19-32.

Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010;5:69.

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#### 1) Stage 1: Ongoing Consultation

As mentioned above, Arksey and O'Malley (2005)<sup>18</sup> suggest ongoing consultation to occur at the end of the scoping review process however as noted by Grant et al (2015)<sup>34</sup>, we believe ongoing consultation should be at the beginning. As stated by Levac et al (2010)<sup>36</sup>, 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 material. 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.

#### 2) 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'Malley<sup>18</sup> suggest keeping the research question broad but Levac et al (2010)<sup>36</sup> suggest having a broad research question with a clear scope of inquiry and defined outcome. Thus, following Levac et al (2010)<sup>36</sup> our research question is: what is the extent (specifically, scar etiology and patients affected), range (least to most of each scar and patient characteristic studied, for example youngest to oldest patient) of patients and scar severity), and nature (of outcomes) of how scars impact patients from a psychosocial and QOL perspective? Variables that will be examined are the location of the scar (visible or not, defined as any scar on the face, neck, hands, and/or feet), scar etiology, and patient ethnicity, gender, and age (child versus adult). These variables were chosen with the guidance of the scar specialist (JF) and through known debates in the literature regarding scar visibility<sup>37</sup>, etiology<sup>38</sup>, and location<sup>4</sup>, ethnicity<sup>39</sup>, gender<sup>40</sup>, and age<sup>41</sup>.

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 improve clinical care. These variables were chosen with the guidance of the scar specialist and through known debates in the literature regarding scar visibility<sup>37</sup>, etiology<sup>38</sup>, and location<sup>4</sup>, ethnicity<sup>39</sup>, gender<sup>40</sup>, and age<sup>41</sup>.

#### 3) 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 (e.g. 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 Appendix 1: Search Strategy. Second, pertinent journals selected by the scar expert (JF) 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<sup>19,42</sup> 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.

#### 4) Stage 4: Study Selection

Levac et al (2010)<sup>36</sup> 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 (2014)<sup>43</sup> proposes 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: Flowchart.

#### 5) Stage 5: Charting the Data

Similar to the previous stages, charting the data will include synthesizing and interpreting the qualitative results in the included articles by sifting and sorting material based on the key issues and themes<sup>44</sup>. Data extraction will be an iterative process and for guality assurance purposes, two independent coders will extract data from the literature into a pre-formed 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 etiologies, 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 generalized QOL will be utilized. First, we are specifically interested in examining psychosocial health from the framework created by Dr. Lana Zinger (2011)<sup>45</sup> 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 categorized into primary and secondary emotions as per Shaver et al (2001)<sup>46</sup>. In addition, the definition of QOL is provided by the World Health Organization, specifically: "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 World Health Organization defines quality of life as an indicator of well-being as

related to health care.<sup>47</sup> These definitions will be used to define the general well-being not attributed to the psychosocial subcategories as defined above. Please see Figure 2: Framework. As explained in the introduction, given the heterogeneity of psychosocial definitions<sup>22-27</sup>, upon 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.

#### 6) Stage 6: Collating, Summarizing, and Reporting Data

Finally, we will present an overview of data from a quantitative and qualitative perspective. Quantitative analysis will be conducted through SAS<sup>®</sup> (University Edition, SAS Institute Inc., Cary, NC, USA) software and will consist of sub-group analysis of each variable (scar visibility, location, and etiology 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<sup>44</sup>. 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 this data to create guidelines, patient advocacy measures, and ultimately, improve patient care.

#### **Patient and Public Involvement**

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 January 1, 2018 to December 31, 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 etiologies) 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, create treatment guidelines, and ultimately, improve patient care.

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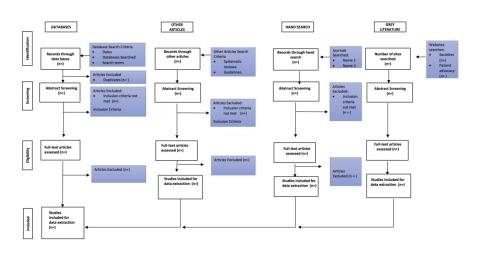
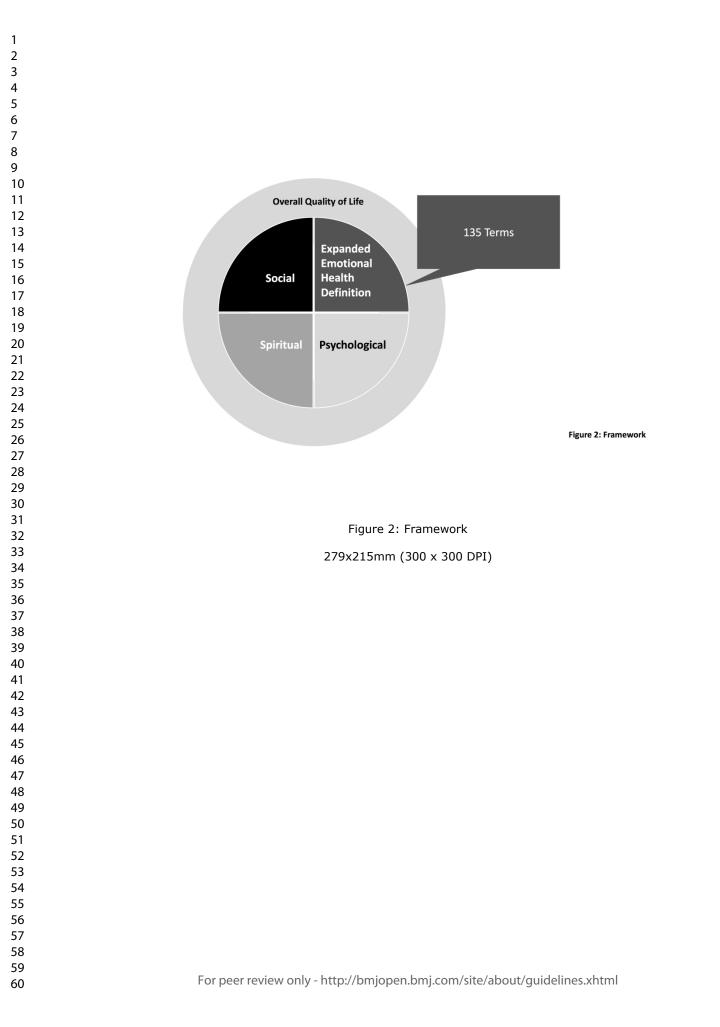


Figure 1: Flowchart



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#### MEDLINE Epub Ahead of Print, In-Process & Other Non-Indexed Citations, and MEDLINE Search Strategy:

#	Searches		
1	cicatrix/ or cicatrix, hypertrophic/ or keloid/ or acne keloid/		
2	(cheloid* or cicatrices or cicatrix or cicatrization or keloid* or scar or scarring or scars or keloidal or keloidalis).tw,kf.		
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5	("self awareness" or "self concept" or "self concepts" or "self confrontation" or "self esteem" or "self esteems" or "self image" or "self perception" or "self perceptions" or "self rating" or "self representation" or "selfconcept").tw,kf.		
6	Self Efficacy/		
7	"self efficacy".tw,kf.		
8	Body Image/		
9	((body or bodily) adj2 (image or images or perception or perceptions or perceive* or representation or representations or schema or schemas)).tw,kf.		
10	"Quality of Life"/		
11	("hrql" or "life qualities" or "life quality" or "quality of life" or "qol").tw,kf.		
12	Sexuality/		
13	(sexuality or psychosexuality or "sexual functioning" or "sexual relation*").tw,kf.		
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16	Social Desirability/		
17	("social* desirab*" or "social* worth*").tw,kf.		
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21	(social* adj2 stigma*).tw,kf.		
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BMJ Open

## **BMJ Open**

# The psychosocial and quality of life impact of scars in the surgical, traumatic, and burn populations: A Scoping Review Protocol

Journal:	BMJ Open
Manuscript ID	bmjopen-2017-021289.R3
Article Type:	Protocol
Date Submitted by the Author:	29-Oct-2018
Complete List of Authors:	Ziolkowski, Natalia; University of Toronto, Surgery; Kitto, Simon; University of Ottawa, Department of Innovation in Medical Education, and the Office of Continuing Professional Development, Faculty of Medicine; University of Toronto, Department of Surgery Jeong, Dahn; University of Ottawa, Department of Innovation in Medical Education, and the Office of Continuing Professional Development, Faculty of Medicine Zuccaro, Jennifer; The Hospital for Sick Children, Division of Plastic and Reconstructive Surgery Adams-Webber, Thomasin; The Hospital for Sick Children, Hospital Library and Archives Miroshnychenko, Anna; McMaster University Faculty of Health Sciences, Pediatrics Fish, Joel; The Hospital for Sick Children, Division of Plastic and Reconstructive Surgery; University of Toronto, Department of Surgery
<b>Primary Subject Heading</b> :	Surgery
Secondary Subject Heading:	Patient-centred medicine, Rehabilitation medicine, Health services research
Keywords:	scar, PLASTIC & RECONSTRUCTIVE SURGERY, psychosocial outcomes, quality of life, burn, SURGERY



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Key Words: cicatrix; quality of life; review; surgery, plastic; burns

Word Count: 2427

Funding: No funding to report.

Competing interests: There are no competing interests.

Contributor Statement:

All authors have made substantive intellectual contributions. NZ, SCK, JSF, TAW were involved in conceptualizing this review. NZ, SCK, JSF were involved in writing this protocol. DJ, JZ, AM, TAW commented critically on several drafts of this manuscript.

#### 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 etiologies 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 summarize the extent, range, and nature of psychosocial health outcomes and QOL of scars of

#### Methods and Analysis:

all etiologies.

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, summarizing, and reporting data. Experts will include a health information specialist (TA-W), scar expert(JF), scoping review consultant(SK), 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.

#### 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 TBSA), and the scoping review process is time-consuming

#### BACKGROUND

Millions of people develop scars from burn injuries, surgeries, and traumatic events.<sup>1-3</sup> 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 selfconsciousness<sup>4</sup>, traumatic scars can have the potential to impair social functioning and emotional well-being,<sup>5</sup> and burn scar have been shown to decrease physical functioning<sup>6</sup>. Recently, hypertrophic scars have been labelled the greatest unmet challenge both psychosocially and functionally to burn rehabilitation<sup>7</sup>.

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 World Health Organization's definition of health that encompasses not only physical but also mental and social well-being<sup>8</sup>. 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 burn<sup>9-11</sup> and traumatic injuries<sup>12-16</sup> do exist but a comprehensive review has not been conducted across all scar etiologies. 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<sup>17</sup>.

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 synthesize quantitative findings, aim to investigate the extent (scar etiology 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<sup>18,19</sup> especially when a topic has either not been extensively reviewed, is complex, or heterogeneous<sup>20</sup>. In particular, scoping reviews map a given field of study, identify gaps in the current state of knowledge, and aim to disseminate findings<sup>18</sup>. 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 etiologies given the conceptual generalizability and transferability<sup>21</sup> of results ensured by the methodological rigor in the scoping review process<sup>21</sup>.

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 (2002)<sup>22</sup> 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<sup>23,24</sup>, well-being, life satisfaction, self-esteem, and overall QOL<sup>25</sup>. It has also been examined with particular disease states such as depression<sup>24-27</sup>, anxiety<sup>26,27</sup>, and emotions such as distress<sup>26</sup> in various clinical studies. Given the multiple definitions and lack of standardization 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.

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The purpose of this protocol is to describe the methodological considerations that will guide the completion of a scoping review that will summarize the extent, range, and nature of psychosocial health and QOL outcomes of scars of all etiologies. Poor psychosocial outcomes have been associated with delayed recovery<sup>28</sup>, chronic disease progression and even mortality<sup>29-31</sup> and the World Health Organization has indicated that psychosocial risks have become a major health concern<sup>32,33</sup>. We are interested in approaching the scar literature from a holistic viewpoint encompassing all types of scar etiologies. This is an uncommon way of approaching the research question as the literature tends to be described using one scar etiology. We are aiming to capture the full range of psychosocial outcomes from the perspective of patients with scars from different etiologies (i.e. scar from a major trauma, vs. a small scar from spilled tea vs. acne or self-harm scars etc). We aim to identify the gaps in knowledge that may exist in terms of understanding how a scar may impact the psychosocial wellbeing 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'Malley<sup>18</sup> framework will be used in this scoping review. The original methodological framework of how to conduct a scoping review by Arksey and O'Malley (2005) includes six major stages: (1) identifying the research question/s, (2) identifying the relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing, and reporting data, and an optional stage, (6) ongoing consultation<sup>18</sup>. This framework has been used to structure a number of scoping reviews in other areas of research<sup>19,34,35</sup>. However, similar to Grant et al (2015)<sup>34</sup>, we feel that the optional stage 6, ongoing consultation, should be included as a first stage. Arksey and O'Malley (2005)<sup>18</sup> 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 (2010)<sup>36</sup> 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. Please refer to Table 1: Comparison of Methods and Overview of Stages.

Table 1: Comparison of Methods and Overview of Stages.

Arksey and O'Malley Stage <sup>18</sup>	Arksey and O'Malley Details/Stage	Levac et al <sup>36</sup> Modifications to Framework	<b>Overview of Phases</b>
Ongoing Consultation*	1) Optional stage completed at end	<ol> <li>Essential stage</li> <li>Establish purpose</li> <li>Articulate type of stakeholder to consult &amp; how data will be collected, analyzed, reported, and integrated</li> </ol>	Stakeholders: 1) Scoping review expert (SK) 2) Scar expert (JF) 3) Health information specialist (TA-W) 4) Two coders (AM, NZ)

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Identifying Research Questions	1) Wide approach to scoping review research question including population, interventions or outcome	<ol> <li>Research Question, consider:         <ul> <li>a) concept</li> <li>b) target</li> <li>population</li> <li>c) health</li> <li>outcomes of</li> <li>interest</li> </ul> </li> <li>Consider the</li> <li>intended outcome to</li> <li>help determine</li> </ol>	<ol> <li>Research Question:         <ul> <li>a) scars</li> <li>b) individuals with scars</li> <li>c) to determine the impact on psychosocial health and QOL</li> <li>2) Outcomes:                 <ul> <li>a) have a better</li> <li>understanding of the wide ranging impact</li> <li>of scars on the individual in order to change clinical care, formulate research</li> <li>questions, and improve patient care</li> </ul> </li> </ul> </li> </ol>
Identify Relevant Studies	Identify studies via: 1) electronic databases 2) reference list 3) hand-searching of key journals 4) existing networks, relevant organizations, conferences Consider: 1) language 2) time span	<ol> <li>Research question and purpose guides decision-making</li> <li>Team</li> </ol>	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	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Full text articles that meet criteria</li> </ol>	<ol> <li>1) Iterative process: constant refinements</li> <li>2) Inclusion &amp; exclusion criteria discussed a priori, 2 coders will independently review articles</li> <li>3) Coders meet at</li> </ol>	<ol> <li>Post hoc inclusion and exclusion criteria after familiarization of data</li> <li>Iterative process: constant refinement</li> <li>Inclusion &amp; exclusion criteria discussed a priori, 2</li> </ol>

		beginning, midpoint, and final stage 4) Any disagreements resolved by third party	coders independently review articles (afte 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: synthesizing and interpreting qualitative data by sifting, charting, sorting material based on key issues and themes	<ol> <li>Create a data extraction a priori</li> <li>Data extraction – iterative process</li> <li>2 independent authors extract data</li> </ol>	Charting, synthesizing, interpreting qualitative data by sifting, charting, sorting material based on key issues and themes by an iterative process of: 1) Creating a data extraction a priori with 2 independent authors extract data
Collating, Summarizing, and Reporting Data	<ol> <li>Present overview of all material reviewed</li> <li>Summarize data extracted</li> <li>Identify research gaps</li> </ol>	<ol> <li>1) Data analysis – quantitative and qualitative</li> <li>2) Report results</li> <li>3) Complete desired outcome</li> <li>4) Discuss implications for future research</li> </ol>	<ol> <li>Present overview of data</li> <li>Summarize data extracted</li> <li>Report results</li> <li>Complete guideline</li> <li>Identify research gaps and discuss implications for future research</li> </ol>

\*Ongoing consultation will occur throughout the scoping review process<sup>34</sup> References:

Arksey H & O'Malley L. Scoping Studies: Towards A Methodological Framework. *Int J Soc Res Methodol* 2005;8(1):19-32.

Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci.* 2010;5:69.

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## 1) Stage 1: Ongoing Consultation

As mentioned above, Arksey and O'Malley (2005)<sup>18</sup> suggest ongoing consultation to occur at the end of the scoping review process however as noted by Grant et al (2015)<sup>34</sup>, we believe ongoing consultation should be at the beginning. As stated by Levac et al (2010)<sup>36</sup>, 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 material. 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.

## 2) 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'Malley<sup>18</sup> suggest keeping the research question broad but Levac et al (2010)<sup>36</sup> suggest having a broad research question with a clear scope of inquiry and defined outcome. Thus, following Levac et al (2010)<sup>36</sup> 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 etiology, and patient ethnicity, gender, and age (child versus adult). These variables were chosen with the guidance of the scar specialist (JF) and through known debates in the literature regarding scar visibility<sup>37</sup>, etiology<sup>38</sup>, and location<sup>4</sup>, ethnicity<sup>39</sup>, gender<sup>40</sup>, and age<sup>41</sup>.

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 improve clinical care. These variables were chosen with the guidance of the scar specialist and through known debates in the literature regarding scar visibility<sup>37</sup>, etiology<sup>38</sup>, and location<sup>4</sup>, ethnicity<sup>39</sup>, gender<sup>40</sup>, and age<sup>41</sup>.

## 3) 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 (e.g. 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 Appendix 1: Search Strategy. Second, pertinent journals selected by the scar expert (JF) 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

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review best practice guidelines, grey literature<sup>19,42</sup> 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.

#### 4) Stage 4: Study Selection

Levac et al (2010)<sup>36</sup> 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 (2014)<sup>43</sup> proposes 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: Flowchart.

#### 5) Stage 5: Charting the Data

Similar to the previous stages, charting the data will include synthesizing and interpreting the qualitative results in the included articles by sifting and sorting material based on the key issues and themes<sup>44</sup>. Data extraction will be an iterative process and for quality assurance purposes, two independent coders will extract data from the literature into a pre-formed 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 etiologies, 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 generalized QOL will be utilized. First, we are specifically interested in examining psychosocial health from the framework created by Dr. Lana Zinger (2011)<sup>45</sup> 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 categorized into primary and secondary emotions as per Shaver et al (2001)<sup>46</sup>. In addition, the definition of QOL is provided by the World Health Organization, specifically: "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 World Health Organization defines quality of life as an indicator of well-being as related to health care.<sup>47</sup> These definitions will be used to define the general well-being not

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attributed to the psychosocial subcategories as defined above. Please see Figure 2: Framework. As explained in the introduction, given the heterogeneity of psychosocial definitions<sup>22-27</sup>, upon 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.

#### 6) Stage 6: Collating, Summarizing, and Reporting Data

Finally, we will present an overview of data from a quantitative and qualitative perspective. Quantitative analysis will be conducted through SAS<sup>®</sup> (University Edition, SAS Institute Inc., Cary, NC, USA) software and will consist of sub-group analysis of each variable (scar visibility, location, and etiology 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<sup>44</sup>. 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 this data to create guidelines, patient advocacy measures, and ultimately, improve patient care.

#### **Patient and Public Involvement**

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 January 1, 2018 to December 31, 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 etiologies) 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, create treatment guidelines, and ultimately, improve patient care.

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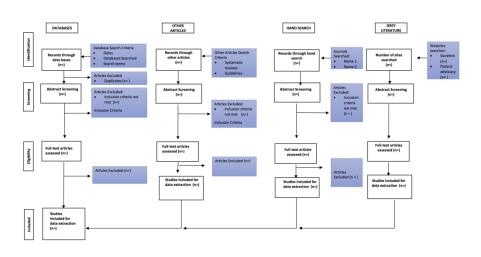
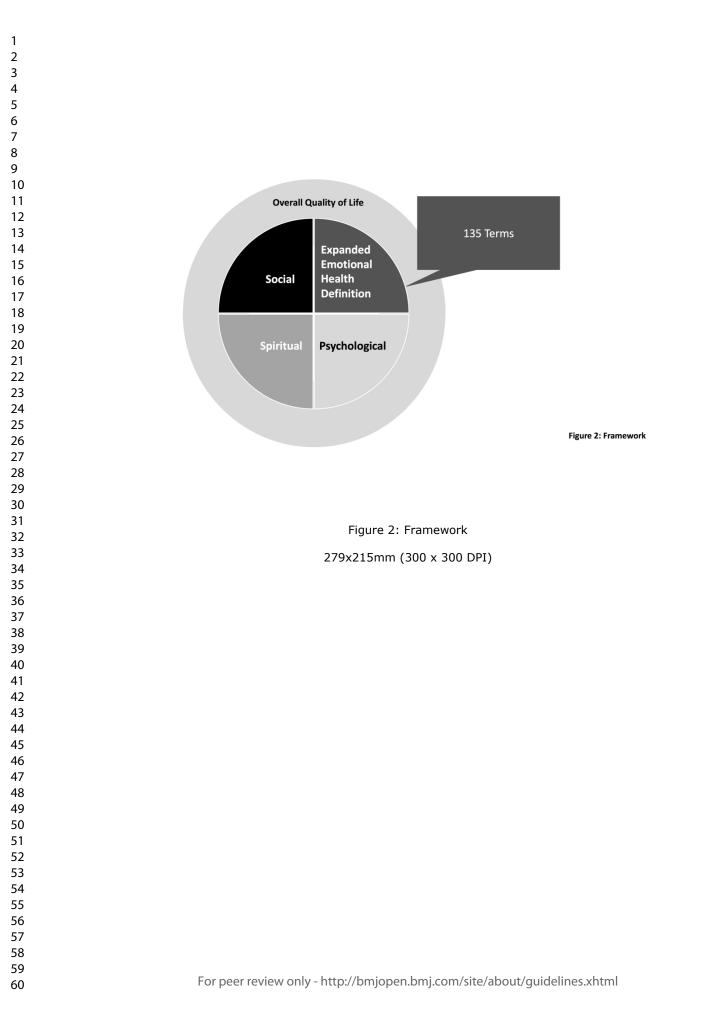


Figure 1: Flowchart



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1       cicatrix/ or cicatrix, hypertrophic/ or keloid/ or acne keloid/         2       (cheloid* or cicatrices or cicatrix or cicatrization or keloid* or scar or scarring or scars or keloidal or keloidalis).tw,kf.         3       1 or 2         4       Self Concept/         ("self awareness" or "self concept" or "self concepts" or "self confrontation" or "self esteem" or self esteems" or "self concept").tw,kf.         6       Self Efficacy/         7       "self efficacy".tw,kf.         8       Body Image/         9       (lbody or bodily) adj2 (image or images or perception or perceptions or perceive* or representation or representations or schema or schemas)).tw,kf.         10       "Quality of Life"/         11       ("hrqi" or "life qualities" or "life quality" or "quality of life" or "qol").tw,kf.         13       (sexuality or psychosexuality or "sexual functioning" or "sexual relation*").tw,kf.         14       social adjustment/ or social adjustments" or "social adaption" or "social responsiveness" or "social ability" or "social ability" or "social adjustments" or "social social responsiveness" or "social abilities" or "social ability" or "social adjustments" or "social skills" or "social abilities" or "social ability" or "social competence").tw,kf.         15       Social Isolation/       10         16       Social solation/       11         17       "social ability or "social ability" or "social adjustments" or "social responsiveness" or	#	Searches
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4       Self Concept/         ("self awareness" or "self concept" or "self concepts" or "self confrontation" or "self esteem" or         5       "self esteems" or "self image" or "self perception" or "self perceptions" or "self rating" or "self         6       Self Efficacy/         7       "self awareness" or "self image" or images or perception or perceptions or perceive* or         9       ((body or bodily) adj2 (image or images or perception or perceptions or perceive* or         10       "quality of Life"/         11       ("hrql" or "life qualities" or "life quality" or "quality of life" or "qol").tw,kf.         12       Sexuality/         13       (sexuality or psychosexuality or "secual functioning" or "secual relation*").tw,kf.         14       social adjustment/ or social akills" or "interpersonal skills" or "interpersonal skills" or "interpersonal skills" or "social adaption" or "social responsiveness" or         15       "social abilities" or "social akill" or "social adaption" or "social responsiveness" or         16       Social pesirability/         17       "social abilities" or "social akill" or "interpersonal skills" or "interpersonal skills" or "interpersonal skills" or "social solatist"         16       Social losiatisolat*" or "isolat* social*").tw,kf.       11         17       "social solation/       11         19       ("social* adj2 stigma*).tw,kf.       12	2	
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7       "self efficacy".tw,kf.         8       Body Image/         9       ((body or bodily) adj2 (image or images or perception or perceptions or perceive* or representation or representations or schema or schemas)).tw,kf.         10       "Quality of Life"/         11       ("hrql" or "life qualities" or "life quality" or "quality of life" or "qol").tw,kf.         12       Sexuality/         13       (sexuality or psychosexuality or "sexual functioning" or "sexual relation*").tw,kf.         14       social adjustment/ or social skills/         ("social adjustment" or "social adjustments" or "social adaption" or "social responsiveness" or "social sensitivity" or "social skills" or "interpersonal skill" or "interpersonal skills" or "social skills" or "social adaption/         15       Social Desirability/         16       Social lealisolation/         19       ("social* desirab*" or "social* worth*").tw,kf.         18       Social Stigma/         20       Social Stigma/         21       (social* adj2 stigma*).tw,kf.         22       Anxiety/         23       (anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.         24       Fear/         25       (fear or fears).tw,kf.         26       shame/         27       (shame or ashamed).tw,kf.         28	5	"self esteems" or "self image" or "self perception" or "self perceptions" or "self rating" or "self
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<ul> <li><sup>9</sup> representation or representations or schema or schemas)).tw,kf.</li> <li>10 "Quality of Life"/</li> <li>11 ("hrql" or "life qualities" or "life quality" or "quality of life" or "qol").tw,kf.</li> <li>12 Sexuality/</li> <li>13 (sexuality or psychosexuality or "sexual functioning" or "sexual relation*").tw,kf.</li> <li>14 social adjustment/ or social skills/</li> <li>("social adjustment" or "social adjustments" or "social adaption" or "social responsiveness" or</li> <li>15 "social abilities" or "social skill" or "social skills" or "interpersonal skill" or "interpersonal skill" or "social abilities" or "social abilities" or "social ability" or "social ability" or "social competence").tw,kf.</li> <li>16 Social Desirability/</li> <li>17 ("social* desirab*" or "isolat* social*").tw,kf.</li> <li>18 Social Isolation/</li> <li>19 ("social* adj2 stigma*).tw,kf.</li> <li>22 Anxiety/</li> <li>23 (anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.</li> <li>24 Fear/</li> <li>25 (fear or fears).tw,kf.</li> <li>26 shame/</li> <li>27 (shame or ashamed).tw,kf.</li> <li>28 Happiness/</li> <li>29 (happiness or happy).tw,kf.</li> <li>30 (personal* adj2 staisf*).tw,kf.</li> <li>31 Resilience, Psychological/</li> <li>32 (hopelessness or despair).tw,kf.</li> </ul>	8	Body Image/
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<ul> <li>15 "social sensitivity" or "social skill" or "interpersonal skill" or "interpersonal skills" or "social abilities" or "social ability" or "social competence").tw,kf.</li> <li>16 Social Desirability/</li> <li>17 ("social* desirab*" or "social* worth*").tw,kf.</li> <li>18 Social Isolation/</li> <li>19 ("social* isolat*" or "isolat* social*").tw,kf.</li> <li>20 Social Stigma/</li> <li>21 (social* adj2 stigma*).tw,kf.</li> <li>22 Anxiety/</li> <li>23 (anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.</li> <li>24 Fear/</li> <li>25 (fear or fears).tw,kf.</li> <li>26 shame/</li> <li>27 (shame or ashamed).tw,kf.</li> <li>28 Happiness/</li> <li>29 (happiness or happy).tw,kf.</li> <li>31 Resilience, Psychological/</li> <li>32 (hopelessness or despair).tw,kf.</li> </ul>	14	social adjustment/ or social skills/
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18       Social Isolation/         19       ("social* isolat*" or "isolat* social*").tw,kf.         20       Social Stigma/         21       (social* adj2 stigma*).tw,kf.         22       Anxiety/         23       (anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.         24       Fear/         25       (fear or fears).tw,kf.         26       shame/         27       (shame or ashamed).tw,kf.         28       Happiness/         29       (happiness or happy).tw,kf.         30       (personal* adj2 satisf*).tw,kf.         31       Resilience, Psychological/         32       (hopelessness or despair).tw,kf.	16	Social Desirability/
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20Social Stigma/21(social* adj2 stigma*).tw,kf.22Anxiety/23(anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.24Fear/25(fear or fears).tw,kf.26shame/27(shame or ashamed).tw,kf.28Happiness/29(happiness or happy).tw,kf.30(personal* adj2 satisf*).tw,kf.31Resilience, Psychological/32(hopelessness or despair).tw,kf.	18	Social Isolation/
21       (social* adj2 stigma*).tw,kf.         22       Anxiety/         23       (anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.         24       Fear/         25       (fear or fears).tw,kf.         26       shame/         27       (shame or ashamed).tw,kf.         28       Happiness/         29       (happiness or happy).tw,kf.         30       (personal* adj2 satisf*).tw,kf.         31       Resilience, Psychological/         32       (hopelessness or despair).tw,kf.	19	("social* isolat*" or "isolat* social*").tw,kf.
<ul> <li>22 Anxiety/</li> <li>23 (anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.</li> <li>24 Fear/</li> <li>25 (fear or fears).tw,kf.</li> <li>26 shame/</li> <li>27 (shame or ashamed).tw,kf.</li> <li>28 Happiness/</li> <li>29 (happiness or happy).tw,kf.</li> <li>30 (personal* adj2 satisf*).tw,kf.</li> <li>31 Resilience, Psychological/</li> <li>32 (hopelessness or despair).tw,kf.</li> </ul>	20	Social Stigma/
<ul> <li>23 (anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.</li> <li>24 Fear/</li> <li>25 (fear or fears).tw,kf.</li> <li>26 shame/</li> <li>27 (shame or ashamed).tw,kf.</li> <li>28 Happiness/</li> <li>29 (happiness or happy).tw,kf.</li> <li>30 (personal* adj2 satisf*).tw,kf.</li> <li>31 Resilience, Psychological/</li> <li>32 (hopelessness or despair).tw,kf.</li> </ul>	21	(social* adj2 stigma*).tw,kf.
24Fear/25(fear or fears).tw,kf.26shame/27(shame or ashamed).tw,kf.28Happiness/29(happiness or happy).tw,kf.30(personal* adj2 satisf*).tw,kf.31Resilience, Psychological/32(hopelessness or despair).tw,kf.	22	Anxiety/
<ul> <li>25 (fear or fears).tw,kf.</li> <li>26 shame/</li> <li>27 (shame or ashamed).tw,kf.</li> <li>28 Happiness/</li> <li>29 (happiness or happy).tw,kf.</li> <li>30 (personal* adj2 satisf*).tw,kf.</li> <li>31 Resilience, Psychological/</li> <li>32 (hopelessness or despair).tw,kf.</li> </ul>	23	(anxieties or anxiety or anxious* or hypervigilan* or nervousness).tw,kf.
26       shame/         27       (shame or ashamed).tw,kf.         28       Happiness/         29       (happiness or happy).tw,kf.         30       (personal* adj2 satisf*).tw,kf.         31       Resilience, Psychological/         32       (hopelessness or despair).tw,kf.	24	Fear/
<ul> <li>27 (shame or ashamed).tw,kf.</li> <li>28 Happiness/</li> <li>29 (happiness or happy).tw,kf.</li> <li>30 (personal* adj2 satisf*).tw,kf.</li> <li>31 Resilience, Psychological/</li> <li>32 (hopelessness or despair).tw,kf.</li> </ul>	25	(fear or fears).tw,kf.
28       Happiness/         29       (happiness or happy).tw,kf.         30       (personal* adj2 satisf*).tw,kf.         31       Resilience, Psychological/         32       (hopelessness or despair).tw,kf.	26	shame/
<ul> <li>29 (happiness or happy).tw,kf.</li> <li>30 (personal* adj2 satisf*).tw,kf.</li> <li>31 Resilience, Psychological/</li> <li>32 (hopelessness or despair).tw,kf.</li> </ul>	27	(shame or ashamed).tw,kf.
30(personal* adj2 satisf*).tw,kf.31Resilience, Psychological/32(hopelessness or despair).tw,kf.	28	Happiness/
31Resilience, Psychological/32(hopelessness or despair).tw,kf.	29	(happiness or happy).tw,kf.
32 (hopelessness or despair).tw,kf.	30	(personal* adj2 satisf*).tw,kf.
	31	Resilience, Psychological/
33 (coping or resilience).tw,kf.	32	(hopelessness or despair).tw,kf.
	33	(coping or resilience).tw,kf.

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34	exp Religion/ or Spirituality/
35	(religio* or spiritual* or buddhis* or christian* or hindu* or islam* or judaism or jewish or confucian* or taois* or sikh*).tw,kf.
36	or/4-35
37	3 and 36
38	cicatrix/px or cicatrix, hypertrophic/px or keloid/px or acne keloid/px
39	37 or 38
40	limit 39 to english language
41	remove duplicates from 40
42	(impact adj15 (cheloid* or cicatrices or cicatrix or cicatrization or keloid* or scar or scarring or scars or keloidal or keloidalis)).tw,kf.
43	limit 42 to english language
44	remove duplicates from 43
45	44 not 41
46	((satisfied or satisfaction or dissatisfied or dissatisfaction or contented or pleased or happy or discontent* or displease* or disappoint* or unhapp*) adj15 (cheloid* or cicatrices or cicatrix or cicatrization or keloid* or scar or scarring or scars or keloidal or keloidalis)).tw,kf.
47	limit 46 to english language
48	remove duplicates from 47