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Complete List of Authors:	Talaat, Habeba; McMaster University Faculty of Health Sciences, Faculty of Health Sciences Bashayan, Seniyyeh; University of Toronto, Department of Psychiatry Sediqzadah, Saadia; University of Toronto, Department of Psychiatry; St Michael's Hospital, Department of Psychiatry Raymakers, Adam; BC Cancer & Simon Fraser University, Bayoumi, Ahmed; St. Michael's Hospital, Centre for Research on Inner City Health, Keenan Research Centre of the Li Ka Shing Knowledge Institute Papatheodorou, Stefania ; Harvard TH Chan School of Public Health,
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Health-related quality of life measures in incarcerated populations: protocol for a scoping review

Habeba Talaat BHSc (candidate)[1], Seniyyeh Bashayan MD[2], Adam J.N. Raymakers PhD[3], Ahmed M. Bayoumi MD, MSc[4-7], Stefania Papatheodorou MD, PhD[8], Saadia Sediqzadah MD, SM[2,9]

Author Affiliations:

[1] Department of Health Science, McMaster University, Hamilton, ON, Canada
[2] Department of Psychiatry, University of Toronto, Toronto, ON, Canada
[3] Faculty of Health Sciences, Simon Fraser University, Burnaby, BC, Canada
[4]MAP Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, ON, Canada
[5]Division of General Internal Medicine, St. Michael's Hospital, Toronto, ON, Canada
[6]Department of Medicine, University of Toronto, Toronto, ON, Canada
[7]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada
[8]Department of Epidemiology, Harvard TH Chan School of Public Health, Boston, MA, USA
[9]Department of Psychiatry, St. Michael's Hospital, Toronto, ON, Canada

Corresponding Author
Habeba Talaat, McMaster University, 1280 Main St. W, Hamilton, ON, L8S4L8. Email: talaath@mcmaster.ca. Phone: 647 473 0395

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Abstract

Introduction

Incarcerated populations represent a vulnerable and marginalized segment of society, with increased health needs and a higher burden of communicable and non-communicable diseases. Traditional population health outcomes do not capture physical, mental, emotional and social well-being. Health related quality of life (HRQoL) outcomes attempt to measure these important parameters. To date, there has not been a scoping review to summarize the HRQoL literature in the incarcerated population. Thus, we aim to perform such a review to inform health policy decisions in incarcerated populations and support health economic evaluations of interventions in incarcerated populations.

Methods and Analysis

We will conduct a scoping review of the literature on the HRQoL in the incarcerated population informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and the corresponding PRISMA Extension for Scoping Reviews. The submissions records of six electronic databases with peer-reviewed literature and three health technology assessment (HTA) agencies will be searched. The search strategy was informed by recommendations for HRQoL reviews. We will include studies that report HRQoL, health state utility values, or reference to quality adjusted life years (QALYs) or quality-adjusted life expectancies of incarcerated populations. No assessments of items' quality will be made, as the purpose of this scoping review is to synthesise and describe the coverage of the evidence. We will also identify knowledge gaps on the HRQoL in the incarcerated population.

Ethics and dissemination

Research ethics approval is not required as primary data will not be collected. The findings of this scoping review will be used to inform health economic analyses for the incarcerated population and will be disseminated through peer-reviewed publications and conference presentations.

Keywords: Health-related quality of life, incarcerated population, scoping review, health utilities

Article Summary

Strengths and limitations of this study

- This is the first scoping review that to focus on the HRQoL in the incarcerated population and will help inform health economic models.
- We will use the PRISMA extension for scoping reviews tool to ensure a systematic methodology to searching, screening and reporting the findings.
- The search for this study will be conducted in journals with multi-disciplinary fields to capture as many relevant articles as possible and to ensure breadth in the findings.
- This scoping review may miss studies that are published outside of journals, such as book chapters or other grey literature.
- Although there are no restrictions to article types and methodologies, only English-language articles will be considered for inclusion.

Introduction

Incarcerated populations have greater health needs and a higher burden of communicable and non-communicable diseases compared to the general population. In a report published by the United States Bureau of Justice Statistics (USBJS) in 2015, prisoners were 1.5 times more likely to report having high blood pressure, diabetes or asthma, relative to the general population.[1] The report also found that the prevalence of viral hepatitis (B or C) in state and federal prisoners was around 10-fold that of the general population.[1] According to the World Health Organization (WHO), prisoners are 15 times more likely to be human immunodeficiency virus (HIV)-positive than those who are not incarcerated.[2] In 2018, the USBJS reported that 14% of prisoners in state and federal facilities met the criteria for having serious mental health conditions, compared to 5% of the general population.[1] Globally, suicide rates in prisons are up to 10 times higher than those in the general population.[3] In a June 2017 USBJS report, 58% of adults who have been in state prisons were estimated to have drug use disorders, compared to 5% of the general adult population.[4] These data highlight the need for preventative and interventional initiatives to reduce the burden of communicable and non-communicable diseases in incarcerated populations.

Diseases may exist prior to incarceration or develop while incarcerated. Incarceration can also perpetuate diseases, particularly those that are communicable. The main risk factors for infectious diseases in prison settings are overcrowding, high-risk sexual behaviour, injection drug use, tattooing and piercing, and lack of access to sterile equipment.[5-7] Additionally, poor screening and access to treatment exacerbates disease transmission and severity. For example, according to the WHO, HIV prevention and treatment programs are rarely available in prison settings.[2] Only about 5% of countries have needle/syringe programs in prisons and many prisoners are unable to access antiretroviral treatment.[2] Furthermore, a study using data from several Italian prisons found that among people with a positive diagnostic test for an infectious disease in prison, the proportions unaware of their disease status were 3.4% of those who were HIV positive (detectable antibodies), 11.6% of those who had chronic hepatitis C virus infection (detectable antibodies), 52.7% of those who had chronic hepatitis B virus infection (detectable surface antigen), and 43.7% of those with latent tuberculosis infection (positive purified protein derivative skin test).[8] These outcomes not only impact incarcerated populations, but also the general population when incarcerated people are released. It is therefore of significant public health concern to prevent, screen, and treat communicable diseases in incarcerated populations.

Incarcerated populations include many people with low educational attainment, unemployment, social isolation, multiple physical and mental health problems, and precarious housing.[9] Incarceration has an important bidirectional relationship with each of these social determinants of health, as both an outcome that is more frequent when these factors are present and a risk factor for these determinants for people who have a history of incarceration.

Population health outcomes traditionally include disease prevalence, life expectancy, and mortality.[10] These outcomes, however, do not capture physical, mental, emotional and social well-being. To evaluate these important outcomes, health-related quality of life (HRQoL) may be useful.[11] There are many reasons for why a society may choose to incarcerate individuals and if one of those reasons is punishment for crime, then incarceration is intended and expected to reduce well-being. How, then, does being incarcerated affect HRQoL outcomes for incarcerated populations? We propose a scoping review to answer this question.

The applications of such a review would inform health policy decisions in incarcerated populations. It will provide a critical review of how HRQoL measures have been utilized in these populations in previous research. The findings may serve to improve future capture of HRQoL in incarcerated populations. We seek to not only capture the overall scores but also disaggregated values for each domain of a HRQoL measure, for the purpose of identifying nuances that can be lost in an average score.[12] If a problem is identified in one or more domains, interventions or policies can be developed to target those specific domains.

Additionally, the findings of this review would be relevant for health economic evaluation, including cost-effectiveness analyses and cost-utility analyses.[13] Cost-utility analyses rely on utility values, typically derived from HRQoL measures for effectiveness outcomes.[13] To the extent that resource allocation decisions for incarcerated populations are informed by economic evaluation, a dearth of HRQoL research may lead to underinvestment in related interventions and result in further marginalization.

A previously published systematic review identified and assessed QoL instruments in incarcerated populations.[14] The author focused on overall QoL and excluded HRQoL instruments because they were interested in a "global evaluation of well-being as defined by the WHO".[14] Our proposed scoping review is therefore unique in that this will be the first study to summarize HRQoL outcomes in incarcerated populations by reviewing articles that utilized preference-based HRQoL instruments.

Scoping Review Objectives

We aim to systematically review the scientific literature for studies that measure HRQoL in incarcerated populations. From these studies, we intend to summarize the findings, highlight any gaps and suggest areas for further study.

Methods and analysis

As we are interested in examining what is known about the HRQoL outcomes in incarcerated populations broadly, we chose to conduct a scoping review. Similar to systematic reviews, scoping reviews use a systematic approach to searching, screening, and reporting. Informed by the Preferred Reporting Items for

Systematic Reviews and Meta-Analyses (PRISMA) and the PRISMA Extension for Scoping Reviews reporting guideline for protocols (PRISMA-ScR), this protocol details our preplanned methodological and analytical approaches.[15,16]

Eligibility criteria

Inclusion criteria will be applied as follows. First, any reference to a preference-based HRQoL instrument, or reference to QALYs, quality-adjusted life expectancies or utility measures in incarcerated populations in the abstract of an identified article will be deemed potentially eligible for inclusion. Further requirements for the papers to be written in English and published in peer-reviewed journals will be incorporated in this stage. Incarcerated population will be defined as individuals who are in detention, with no restrictions regarding age, gender, ethnicity, or prison type. Arrested individuals who stay in police custody, prisoners of war, and prisoners in concentration camps will be excluded. We will include any experimental design, including observational studies. Once we have identified exclusions, full text versions of the remaining articles will be obtained.

Information Sources

We will search the following databases: Medline, PsychInfo, Embase, EconLit, Web of Science, and Cochrane Library. In addition, the following specialised databases will be included: Cost-effectiveness Analysis Registry, National Health System Economic Evaluation database, and the Canadian Agency for Drugs and Technologies in Health. This search will be supplemented by cross-referencing included studies and contacting authors in the field.

Search strategy

The development of our search strategy and search terms were informed by previously published systematic reviews of HRQoL outcomes.[17-19] Specific search terms include different variants and iterations of prisoner terms (convict, inmate, offender, etc.), preference-based HRQoL instruments terms (15-dimensional, Assessment of Quality of Life (AQoL)-4D, AQoL-6D, EuroQol- 5 Dimension, Health Utilities Index (HUI)-2, HUI-3, Quality of Well-Being Scale Self-Administered (QWB-SA), Short-Form Six-Dimension, etc.), HRQoL and QoL. A sample search strategy is provided in the online Supplementary Appendix 1.

Selection process

Two investigators (HT and SB) will review the titles and abstracts independently, assessing them for inclusion. If a study meets the inclusion criteria or if there are doubts regarding the inclusion of the study then we will retrieve the full text of the article. Full text articles will also be reviewed independently by both reviewers. In case of any disagreement about inclusion, full-text articles will be reviewed again by both reviewers and if an agreement cannot be reached, this will be resolved by involving a third reviewer (SS). Reasons for exclusions will be documented for all full text articles and the full list of excluded articles with reasons for exclusion will be provided.

Data Extraction and Management

Data extraction will be conducted independently by two investigators (HT and SB) and entered into an electronic spreadsheet. If there is a disagreement between data entries, it will be resolved by discussion with a third author (SS). If there are missing data or doubts about the data, authors of papers under consideration will be contacted. Literature search results will be managed using Covidence software.

Data Items

Data extraction items will include: description of the study background, participant characteristics, method of elicitation of HRQoL values and health state utility values, and description of the results and findings of the study. We included relevant components from the Checklist for REporting VAluaTion StudiEs (CREATE) checklist (such as the descriptive system, health states valued, sampling, and study sample) to inform our data extraction items.[20] Details regarding the data extraction items can be found in the Supplementary Appendix 2.

Quality assessment of individual studies

Assessment of the risk of bias of individual studies is not conducted for scoping reviews since we do not aim to produce a critically appraised or synthesized result. Rather, we will be mapping the body of literature and identifying gaps in this field.[21]

Data Synthesis

As a scoping review, the purpose of this study is to aggregate the findings and present an overview of the research rather than to evaluate the quality of the individual studies. Our overall assessment of the strength of the evidence will therefore be narrative rather than quantitative using statistical methods. We will report the data using a systematic narrative synthesis in which the results are presented narratively and organised thematically, supplemented with tables of descriptive statistics on included studies and their outcomes.

Discussion

Incarcerated populations experience marginalization, with health needs that are often inadequately met. To the best of our knowledge, there are no reviews that specifically assess HRQoL outcomes in incarcerated populations. Thus, this scoping review aims to map the existing literature on HRQoL in these populations and contribute to the health informatics evidence base. Understanding the HRQoL of incarcerated populations can inform health policy and health economic evaluation in this segment of society.

Ethics and dissemination

Approval from a research ethics board will not be required as original data will not be collected as part of this scoping review. Information will be synthesized from available secondary sources. We anticipate the results of this review will provide a comprehensive overview of the evidence base and it will also provide key information to inform health economic analyses in the incarcerated population as stated above. The completed scoping review will be submitted to peer-reviewed journals and presentations at conferences.

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Footnotes

Author Contributions

HT, SS and SB authors participated in the design, drafting and revising of the scoping review protocol manuscript. AR, AB and SP participated in the editing of the scoping review protocol draft and all authors participated in the final approval of this scoping review protocol manuscript.

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Competing interests

None declared.

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Supplementary Appendix 1

OVID Medline Search

1. (SF-6D or sf6d or "sf 6d").ti,ab,kf.
2. (euro$ adj3 (5 d or 5d or 5 dimension$ or 5dimension$ or 5 domain$ or 5domain$)).ti,ab,kf.
3. Quality-Adjusted Life Years/
4. (quality adjusted or adjusted life year$).ti,ab,kf.
5. (qaly$ or qald$ or qale$ or qtime$).ti,ab,kf.
6. (illness state$1 or health state$1).ti,ab,kf.
7. (hui or hui1 or hui2 or hui3).ti,ab,kf.
8. (multiattribute$ or multi attribute$).ti,ab,kf.
9. (utility adj3 (score$1 or valu$ or health$ or cost$ or measur$ or disease$ or mean or gain or gains or index$)).ti,ab,kf.
10. utilities.ti,ab,kf.
11. (eq-5d or eq5d or eq-5 or eq5 or euro qual or euroqual or euro qual5d or euroqual5d or euro qol or euroqol or euro qol5d or euroqol5d or euro quol or euroquol or euro quol5d or euroquol5d or eur qol or eurqol or eur qol5d or eur qol5d or eur?qul or eur?qul5d or euro$ quality of life or european qol).ti,ab,kf.
12. (euro$ adj3 (5 d or 5d or 5 dimension$ or 5dimension$ or 5 domain$ or 5domain$)).ti,ab,kf.
13. (sf36$ or sf 36$ or sf thirtysix or sf thirty six).ti,ab,kf.
14. (time trade off$1 or time tradeoff$1 or tto or timetradeoff$1).ti,ab,kf.
15. quality of life/ and ((quality of life or qol) adj (score$1 or measure$1)).ti,ab,kf.

16. quality of life/ and ec.fs.
17. quality of life/ and (health adj3 status).ti,ab,kf.
18. (quality of life or qol).ti,ab. and Cost-Benefit Analysis/
19. (quality of well being" or "quality of wellbeing" or "quality of well-being" or "QWB").ti,ab,kf. 20. ("Quality of Well Being Self-Administered" or "Quality of Well-Being Self-Administered" or QWB-SA).ti,ab,kf.
21. ("Assessment of Quality of Life" or AQoL).ti,ab,kf.
22. (15D or 15-D or 15-dimensional or "15 dimensional").ti,ab,kf.
23. (Prison* or "Prison Population" or Incarcerat* or Convict* or Inmate* or Detention* or Offender* or Criminal* or Imprison* or Jail* or Detainee*).ti,ab,kf.
24. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
25. 23 and 24

Supplementary Appendix 2

Study identifiers	Study participant characteristics	Method of elicitation of HRQoL values and HSUVs	Description of results and findings of the study:
ID: Author: Article title: Year: Country of respondents: Conflict of interest: Funding source: Study design: Exclusions: Study setting:	Sample size: Sampling strategy and rationalization: Recruitment strategies: Inclusion and exclusion criteria: Description of intervention and comparator (when applicable): Age: Sex: Race: Socioeconomic status: Diagnosis: Disease severity:	Instruments used: Mode of administration: Direct or indirect measurement of HSUVs: Self-reported or by a proxy (eg. prison staff or healthcare provider): Follow-up duration:	Response rates: Reasons for missing data: Summary of findings: Limitations of the study identified by authors of the study: Limitations of the study identified by our research team:

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	3
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Manuscript provided is the protocol
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	3
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	3
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary appendix 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	4
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable to protocol

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	4
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Not applicable to protocol
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Not applicable to protocol
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable to protocol
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Not applicable to protocol
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Not applicable to protocol
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Not applicable to protocol
Limitations	20	Discuss the limitations of the scoping review process.	Not applicable to protocol
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Not applicable to protocol
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	7

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

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Secondary Subject Heading:	Health informatics, Health policy, Qualitative research, Public health
Keywords:	HEALTH ECONOMICS, PUBLIC HEALTH, Health informatics < BIOTECHNOLOGY & BIOINFORMATICS

Health-related quality of life measures in incarcerated populations: protocol for a scoping review

Habeba Talaat BHSc (candidate)[1], Seniyyeh Bashayan MD[2], Adam J.N. Raymakers PhD[3], Ahmed M. Bayoumi MD, MSc[4-7], Stefania Papatheodorou MD, PhD[8], Saadia Sediqzadah MD, SM[2,9]

Author Affiliations:

[1] Department of Health Science, McMaster University, Hamilton, ON, Canada
[2] Department of Psychiatry, University of Toronto, Toronto, ON, Canada
[3] Faculty of Health Sciences, Simon Fraser University, Burnaby, BC, Canada
[4]MAP Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, ON, Canada
[5]Division of General Internal Medicine, St. Michael's Hospital, Toronto, ON, Canada
[6]Department of Medicine, University of Toronto, Toronto, ON, Canada
[7]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada
[8]Department of Epidemiology, Harvard TH Chan School of Public Health, Boston, MA, USA
[9]Department of Psychiatry, St. Michael's Hospital, Toronto, ON, Canada

Corresponding Author
Habeba Talaat, McMaster University, 1280 Main St. W, Hamilton, ON, L8S4L8. Email: talaath@mcmaster.ca. Phone: 647 473 0395

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Abstract

Introduction

Incarcerated populations represent a vulnerable and marginalized segment of society, with increased health needs and a higher burden of communicable and non-communicable diseases. Traditional population health outcomes do not capture physical, mental, emotional and social well-being. Health related quality of life (HRQoL) outcomes attempt to measure these important parameters. To date, there has not been a scoping review to summarize the HRQoL literature in the incarcerated population. Thus, we aim to perform such a review to inform health policy decisions in incarcerated populations and support health economic evaluations of interventions in incarcerated populations.

Methods and Analysis

We will conduct a scoping review of the literature on the HRQoL in the incarcerated population informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and the corresponding PRISMA Extension for Scoping Reviews. The submissions records of six electronic databases with peer-reviewed literature and three health technology assessment (HTA) agencies will be searched. The search strategy was informed by recommendations for HRQoL reviews. We will include studies that report HRQoL, health state utility values, or reference to quality adjusted life years (QALYs) or quality-adjusted life expectancies of incarcerated populations. No assessments of items' quality will be made, as the purpose of this scoping review is to synthesize and describe the coverage of the evidence. We will also identify knowledge gaps on the HRQoL in the incarcerated population.

Ethics and dissemination

Research ethics approval is not required as primary data will not be collected. The findings of this scoping review will be used to inform health economic analyses for the incarcerated population and will be disseminated through peer-reviewed publications and conference presentations.

Keywords: Health-related quality of life, incarcerated population, scoping review, health utilities

Article Summary

Strengths and limitations of this study

- This scoping review protocol is the first to focus on HRQoL in incarcerated populations.
- The scoping review is being conducted in the context of using preference-based HRQOL measures to inform economic evaluation and will focus on summarizing these data. As such, qualitative findings will not be included.
- This scoping review may miss studies that are published outside of journals, such as book chapters or other grey literature.
- Although there are no restrictions to article types and methodologies, only English-language articles will be considered for inclusion.

Introduction

Incarcerated populations, which we defined as the number of inmates under the jurisdiction of state or federal prisons who are sentenced to more than one year of incarceration.[1] These populations have greater health needs and a higher burden of communicable and non-communicable diseases compared with the general population. In a report published by the United States Bureau of Justice Statistics (USBJS) in 2015, prisoners were 1.5 times more likely to report having high blood pressure, diabetes or asthma, relative to the general population.[2] The report also found that the prevalence of viral hepatitis B or C in state and federal prisoners was around 10-fold that of the general population.[2] According to the World Health Organization (WHO), prisoners are 15 times more likely to be human immunodeficiency virus (HIV)-positive than those who are not incarcerated.[3] In 2018, the USBJS reported that 14% of prisoners in state and federal facilities met the criteria for having serious mental health conditions, compared with 5% of the general population.[2] Globally, suicide rates in prisons are up to 10 times higher than those in the general population.[4] In a June 2017 USBJS report, 58% of adults who have been in state prisons were estimated to have drug use disorders, compared with 5% of the general adult population.[5] These data highlight the need for preventative and interventional initiatives to reduce the burden of communicable and non-communicable diseases in incarcerated populations.

Diseases may exist prior to incarceration or develop while incarcerated. Incarceration can also perpetuate diseases, particularly those that are communicable. The main risk factors for infectious diseases in prison settings are overcrowding, high-risk sexual behaviour, injection drug use, tattooing and piercing, and lack of access to sterile equipment.[6-8] Additionally, poor screening and access to treatment exacerbates disease transmission and severity. For example, according to the WHO, HIV prevention and treatment programs are rarely available in prison settings.[3] Only about 5% of countries have needle/syringe programs in prisons and many prisoners are unable to access antiretroviral treatment.[3] Furthermore, a study using data from several Italian prisons found that among people with a positive diagnostic test for an infectious disease in prison, the proportions unaware of their disease status were 3.4% of those who were HIV positive (detectable antibodies), 11.6% of those who had chronic hepatitis C virus infection (detectable antibodies), 52.7% of those who had chronic hepatitis B virus infection (detectable surface antigen), and 43.7% of those with latent tuberculosis infection (positive purified protein derivative skin test).[9] These outcomes not only impact incarcerated populations, but also the general population when incarcerated people are released. It is therefore of significant public health concern to prevent, screen, and treat communicable diseases in incarcerated populations.

Incarcerated populations include many people with low educational attainment, unemployment, social isolation, multiple physical and mental health problems, and precarious housing.[10] Incarceration has an important bidirectional relationship with each of these social determinants of health, as both an outcome that is more frequent when these factors are present and a risk factor for these determinants for people who have a history of incarceration.

Population health outcomes traditionally include disease prevalence, life expectancy, and mortality.[11] These outcomes, however, do not capture physical, mental, emotional and social well-being. To evaluate these important outcomes, HRQoL may be useful.[12] There are many reasons why a society may choose to incarcerate individuals and if one of those reasons is punishment for crime, then incarceration is intended and expected to reduce well-being. How, then, does being incarcerated affect HRQoL outcomes for incarcerated populations? We propose a scoping review to answer this question.

Quality of life (QoL) is a measure of overall well-being, including physical, social and emotional aspects of life. We conceptualize HRQoL as the intersection between conventional QoL assessments and health status and functioning.[13, 14]

There are two main approaches to measuring HRQoL: generic instruments that provide an overview of HRQoL, and specific instruments that relate to a particular disease or group.[15] This study will summarize the findings of generic instruments to provide a broad overview of incarcerated populations. One focus of this work will be on measures that can generate utility weights, which are summary HRQoL measures anchored at death (0) and best possible health (1) (although states worse than death are included in some utility scales).[15] Utility measures are recommended for use in health economic analysis; however,the quantitative measure of HRQoL is a disadvantage as a single numeric score can constrain data interpretation.[15]

Utility scores are commonly derived from preference-based measures of HRQoL.[15] The valuation component of preference-based HRQoL instruments is a procedure for scoring each health state defined by the questionnaire.[15] Commonly used preference-based HRQoL instruments include: the 15D, the Assessment of Quality of Life (AQoL), the EQ-5D, the Health Utilities Index (HUI), the Quality of Well-Being Scale (QWB), and the SF-6D.[15] This scoping review will focus on generic preference-based HRQoL instruments.[15]

Previously published literature suggests that prisoners' health and HRQoL can be significantly affected by the prison environment. A cross-sectional study conducted in 2013 assessed the HRQoL in a male prison in Greece.[16] They used the 36-Item Short Form Survey (SF-36) and the EQ-5D HRQoL instruments.[16] They reported that prisoners had high values in all scales of the SF-36 instrument except for the mental health scale.[16] Among the different EQ-5D dimensions, the majority of the prisoners had no problems with mobility, self-care, usual activities, or pain/discomfort. By contrast, for the dimension of anxiety/depression, many respondents reported having some/extreme problems.[16] The authors found that prisoners saw the greatest toll on their mental health, while improvement in HRQoL is associated with being able to leave the prison regularly on temporary license.[16] They concluded that the conditions of incarceration influenced HRQoL.[16]

We will provide a critical review of how HRQoL measures have been utilized in these populations in previous research. The applications of such a review would inform health policy decisions in incarcerated populations. The findings may serve to improve future capture of HRQoL in incarcerated populations. We seek to not only capture the overall scores but also disaggregated values for each domain of a HRQoL measure, for the purpose of identifying nuances that can be lost in an average score.[17] If a problem is identified in one or more domains, interventions or policies can be developed to target those specific domains.

Additionally, the findings of this review would be relevant for health economic evaluation, including cost-effectiveness analyses and cost-utility analyses.[18] Cost-utility analyses rely on utility values, typically derived from HRQoL measures for effectiveness outcomes.[18] To the extent that resource allocation decisions for incarcerated populations are informed by economic evaluation, a dearth of HRQoL research may lead to underinvestment in related interventions and result in further marginalization.

A previously published systematic review identified and assessed QoL instruments in incarcerated populations.[19] The author focused on overall QoL and excluded HRQoL instruments because they were interested in a "global evaluation of well-being as defined by the WHO".[19] Our proposed scoping review is therefore unique in that this will be the first study to summarize HRQoL outcomes in incarcerated populations by reviewing articles that utilized preference-based HRQoL instruments.

Scoping Review Objectives

We aim to systematically review the scientific literature for studies that measure HRQoL in incarcerated populations. From these studies, we intend to summarize the findings, highlight any gaps and suggest areas for further study.

Methods and Analysis

As we are interested in examining what is known about the HRQoL outcomes in incarcerated populations broadly, we are planning a scoping review. Similar to systematic reviews, scoping reviews use a systematic approach to searching, screening, and reporting. Informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and the PRISMA Extension for Scoping Reviews reporting guideline for protocols (PRISMA-ScR), this protocol details our preplanned methodological and analytical approaches.[20,21]

Patient and Public Involvement

No patient involved.

Eligibility Criteria

Inclusion criteria will be applied as follows. First, any reference to a preference-based HRQoL instrument (as explained above in the introduction), or reference to QALYs, quality-adjusted life expectancies or utility measures in incarcerated populations in the abstract of an identified article will be deemed potentially eligible for inclusion. Further requirements for the papers to be written in English and published in peer-reviewed journals will be incorporated in this stage. "Incarcerated population" will be defined as individuals who are in detention in prisons designed to hold inmates serving sentences of more than a year, with no restrictions regarding age, gender, or ethnicity.[1] Arrested individuals who stay in police custody, prisoners of war, prisoners in concentration camps, those awaiting trial, sentencing, or transfer to prison, prisoners in psychiatric units, local jails, home detentions and immigration detainees will be excluded.[22] We will include any experimental design, including observational studies. Once we have identified exclusions, full text versions of the remaining articles will be obtained. If full-text articles cannot be obtained, we will contact the authors. If we receive no response, the article will be excluded at

this stage. However, this is an extremely rare situation. A PICO table can be found in Supplementary Appendix 1 summarizing the eligibility criteria for our scoping review.

Information Sources

We will search the following databases: Medline, PsychInfo, Embase, EconLit, Web of Science), and Cochrane Library. In addition, the following specialised databases will be included: Cost-effectiveness Analysis Registry, National Health System Economic Evaluation database, and the Canadian Agency for Drugs and Technologies in Health. There are no date restrictions in our database search. Two investigators (HT and SB) will also be searching reference lists by hand-searching the references of the full-text eligible papers. This search will be supplemented by cross-referencing included studies and contacting authors in the field.

Search Strategy

The development of our search strategy and search terms were informed by previously published systematic reviews of HRQoL outcomes.[23-25] Specific search terms include different variants and iterations of prisoner terms (convict, inmate, offender, etc.), preference-based HRQoL instruments terms (15-dimensional, Assessment of Quality of Life (AQoL)-4D, AQoL-6D, EuroQol- 5 Dimension, Health Utilities Index (HUI)-2, HUI-3, Quality of Well-Being Scale Self-Administered (QWB-SA), Short-Form Six-Dimension, etc.), HRQoL and QoL. A sample search strategy is provided in the online Supplementary Appendix 2.

Selection Process

Two investigators (HT and SB) will review the titles and abstracts independently, assessing them for inclusion. If a study meets the inclusion criteria or if there are doubts regarding the inclusion of the study then we will retrieve the full text of the article. Full text articles will also be reviewed independently by both reviewers. In case of any disagreement about inclusion, full-text articles will be reviewed again by both reviewers and if an agreement cannot be reached, this will be resolved by involving a third reviewer (SS). Reasons for exclusions will be documented for all full text articles and the full list of excluded articles with reasons for exclusion will be provided.

Data Extraction and Management

Data extraction will be conducted independently by two investigators (HT and SB) and entered into an electronic spreadsheet. If there is a disagreement between data entries, it will be resolved by discussion with a third author (SS). If there are missing data or doubts about the data, authors of papers under consideration will be contacted. Literature search results will be managed using Covidence software.

Data Items

Data extraction items will include: description of the study background, participant characteristics, method of elicitation of HRQoL values and health state utility values, and description of the results and findings of the study. We included relevant components from the Checklist for REporting VAluaTion StudiEs (CREATE) checklist (such as the descriptive system, health states valued, sampling, and study sample) to inform our data extraction items.[26] Details regarding the data extraction items can be found in the Supplementary Appendix 3.

Quality Assessment of individual Studies

Assessment of the risk of bias of individual studies is not conducted for scoping reviews since we do not aim to produce a critically appraised or synthesized result. Rather, we will be mapping the body of literature and identifying gaps in this field.[27]

Data Synthesis

As a scoping review, the purpose of this study is to aggregate the findings and present an overview of the research rather than to evaluate the quality of the individual studies. Our overall assessment of the strength of the evidence will therefore be narrative rather than quantitative using statistical methods. We will report the data using a systematic narrative synthesis in which the results are presented narratively and organized thematically, supplemented with tables of descriptive statistics on included studies and their outcomes.

Discussion

Incarcerated populations experience marginalization, with health needs that are often inadequately met. To the best of our knowledge, there are no reviews that specifically assess HRQoL outcomes in incarcerated populations. Thus, this scoping review aims to map the existing literature on HRQoL in these populations and contribute to the health informatics evidence base. Understanding the HRQoL of incarcerated populations can inform health policy and health economic evaluation in this segment of society.

Ethics and Dissemination

Approval from a research ethics board will not be required as original data will not be collected as part of this scoping review. Information will be synthesized from available secondary sources. We anticipate the results of this review will provide a comprehensive overview of the evidence base and it will also provide key information to inform health economic analyses in the incarcerated population as stated above. The completed scoping review will be submitted to peer-reviewed journals and presentations at conferences.

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Footnotes

Author Contributions

HT, SS and SB authors participated in the design, drafting, revising of scoping review protocol manuscript. AR, AB and SP contributed to the conception of the work, participated in the editing of the scoping review protocol draft. All authors participated in the final approval of this scoping review protocol manuscript and agreement to be accountable for all aspects of the work.

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Competing Interests

None declared.

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Supplementary Appendix 1

Eligibility Criteria

PICO	Inclusion Criteria	Exclusion Criteria
Population	• Incarcerated population which are individuals in detention in prisons who are serving sentences for more than a year with no restrictions regarding age, gender or ethnicity	• Arrested individuals who stay in police custody • Prisoners of War • Persons from concentration camps • Immigration detainees • Prisoners in psychiatric units • Those awaiting trial, sentencing, or transfer to prison, • Local jails • Home detentions

Intervention	• Any form of health-related quality of life measurement including but not limited to:
	  • Physical functioning
	  • SF-6D
	  • SF-36
	  • EQ-5D
	  • 15D
	  • QWB
	  • QWB-SA
	  • AQoL-4D
	  • AQoL-6D
	• Any form of health state utility measurement	

Comparison	No comparison group	
Outcomes	• Health-related quality of life value • Health state utility score • Health utility index • Quality-adjusted life year • Quality-adjusted life expectancy	• Exclude non-English articles

Supplementary Appendix 2

OVID Medline Search

1. (SF-6D or sf6d or "sf 6d").ti,ab,kf.
2. (euro$ adj3 (5 d or 5d or 5 dimension$ or 5dimension$ or 5 domain$ or 5domain$)).ti,ab,kf.
3. Quality-Adjusted Life Years/
4. (quality adjusted or adjusted life year$).ti,ab,kf.
5. (qaly$ or qald$ or qale$ or qtime$).ti,ab,kf.
6. (illness state$1 or health state$1).ti,ab,kf.
7. (hui or hui1 or hui2 or hui3).ti,ab,kf.
8. (multiattribute$ or multi attribute$).ti,ab,kf.
9. (utility adj3 (score$1 or valu$ or health$ or cost$ or measur$ or disease$ or mean or gain or gains or index$)).ti,ab,kf.
10. utilities.ti,ab,kf.
11. (eq-5d or eq5d or eq-5 or eq5 or euro qual or euroqual or euro qual5d or euroqual5d or euro qol or euroqol or euro qol5d or euroqol5d or euro quol or euroquol or euro quol5d or euroquol5d or eur qol or eurqol or eur qol5d or eur qol5d or eur?qul or eur?qul5d or euro$ quality of life or european qol).ti,ab,kf.
12. (euro$ adj3 (5 d or 5d or 5 dimension$ or 5dimension$ or 5 domain$ or 5domain$)).ti,ab,kf.
13. (sf36$ or sf 36$ or sf thirtysix or sf thirty six).ti,ab,kf.
14. (time trade off$1 or time tradeoff$1 or tto or timetradeoff$1).ti,ab,kf.
15. quality of life/ and ((quality of life or qol) adj (score$1 or measure$1)).ti,ab,kf.

16. quality of life/ and ec.fs.
17. quality of life/ and (health adj3 status).ti,ab,kf.
18. (quality of life or qol).ti,ab. and Cost-Benefit Analysis/
19. (quality of well being" or "quality of wellbeing" or "quality of well-being" or "QWB").ti,ab,kf. 20. ("Quality of Well Being Self-Administered" or "Quality of Well-Being Self-Administered" or QWB-SA).ti,ab,kf.
21. ("Assessment of Quality of Life" or AQoL).ti,ab,kf.
22. (15D or 15-D or 15-dimensional or "15 dimensional").ti,ab,kf.
23. (Prison* or "Prison Population" or Incarcerat* or Convict* or Inmate* or Detention* or Offender* or Criminal* or Imprison* or Jail* or Detainee*).ti,ab,kf.
24. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
25. 23 and 24

Supplementary Appendix 3

Study identifiers	Study participant characteristics	Method of elicitation of HRQoL values and HSUVs	Description of results and findings of the study:
ID: Author: Article title: Year: Country of respondents: Conflict of interest: Funding source: Study design: Exclusions: Study setting:	Sample size: Sampling strategy and rationalization: Recruitment strategies: Inclusion and exclusion criteria: Description of intervention and comparator (when applicable): Age: Sex: Race: Socioeconomic status: Diagnosis: Disease severity:	Instruments used: Mode of administration: Direct or indirect measurement of HSUVs: Self-reported or by a proxy (eg. prison staff or healthcare provider): Follow-up duration:	HRQoL or HSUV value for the health states reported: Article's aggregated values for HRQoL or HSUV measures present: Response rates: Reasons for missing data: Summary of findings: Limitations of the study identified by authors of the study: Limitations of the study identified by our research team:

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	3
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Manuscript provided is the protocol
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	3
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	3
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary appendix 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	4
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable to protocol

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	4
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Not applicable to protocol
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Not applicable to protocol
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable to protocol
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Not applicable to protocol
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Not applicable to protocol
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Not applicable to protocol
Limitations	20	Discuss the limitations of the scoping review process.	Not applicable to protocol
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Not applicable to protocol
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	7

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

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