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

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ABSTRACT

Introduction Incarcerated populations represent a vulnerable and marginalised 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 summarise 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 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 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.

Strengths and limitations of this study

⇒ This scoping review protocol is the first to focus on health-related quality of life (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 summarising 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 1 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 US 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 WHO, prisoners are 15 times more likely to be 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 programmes are rarely available in prison settings.[3] Only about 5% of countries have needle/syringe programmes 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, health-related quality of life (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.

QoL is a measure of overall well-being, including physical, social and emotional aspects of life. We conceptualise 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 summarise 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 QoL (AQoL), the EuroQol-5 Dimension (EQ-5D), the Health Utilities Index (HUI), the Quality of Well-Being Scale (QWB) and the Short Form Survey 6 Dimension (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 SF (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 used 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 marginalisation.

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 summarise HRQoL outcomes in incarcerated populations by reviewing articles that used 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 summarise 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, 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 quality-adjusted life years, 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 online supplemental appendix 1 summarising the eligibility criteria for our scoping review.

Information sources

We will search the following databases: Medline, PsycINFO, 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 handsearching 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.[15 23 24] Specific search terms include different variants and iterations of prisoner terms (convict, inmate, offender, etc), preference-based HRQoL instruments terms (15-dimensional, AQoL–4D, AQoL-6D, EQ-5D, HUI–2, HUI-3, QWB Self-Administered, Short-Form Six-Dimension, etc), HRQoL and QoL. A sample search strategy is provided in online supplemental 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 checklist (such as the descriptive system, health states valued, sampling and study sample) to inform our data extraction items.[25] Details regarding the data extraction items can be found in the online supplemental apendix 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 synthesised result. Rather, we will be mapping the body of literature and identifying gaps in this field.[26]

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 marginalisation, 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.

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Correction notice This article has been corrected since it first published. 'Dr' has been removed from author name 'Habeba Talaat'.

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