BMJ Open

Palliative and end of life care in prisons: a mixed-methods rapid review of the literature from 2014–2018

Chris McParland ,[1] Bridget Margaret Johnston[1,2]

To cite: McParland C, Johnston BM. Palliative and end of life care in prisons: a mixed-methods rapid review of the literature from 2014–2018. *BMJ Open* 2019;**9**:e033905. doi:10.1136/bmjopen-2019-033905

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2019-033905).

Received 27 August 2019
Revised 12 November 2019
Accepted 28 November 2019

[1]School of Medicine, Dentistry and Nursing, University of Glasgow, Glasgow, UK
[2]NHS Greater Glasgow and Clyde, Glasgow, UK

Correspondence to
Professor Bridget Margaret Johnston;
Bridget.Johnston@glasgow.ac.uk

ABSTRACT

Objectives To explore current practice in relation to palliative and end of life care in prisons, and to make recommendations for its future provision.

Design A rapid literature review of studies using qualitative, quantitative and mixed-methods, with a narrative synthesis of results.

Data sources Six databases searched between January 2014 to December 2018: ASSIA, CINAHL, Embase, MEDLINE, National Criminal Justice Reference Service Abstracts and Scopus.

Eligibility criteria Primary research articles reporting qualitative or quantitative findings about palliative and end of life care in prisons, published in peer-reviewed, English language journals between January 2014 to December 2018.

Participants Prisoners, prisoners' families, prison healthcare staff and other prison staff.

Data extraction/synthesis Data extracted included: citation, design, aim, setting, sample/population, methods and key findings. Data were analysed thematically then subject to a narrative synthesis in order to answer the research questions.

Quality appraisal Two researchers independently appraised articles using the Qualsyst tool, by Kmet *et al* (2004). Aggregate summary quality scores are included with findings. Articles were not excluded based on quality appraisal.

Results 23 articles were included (16 qualitative, 6 quantitative, 1 mixed methods). Top three findings (by prevalence) were: fostering relationships with people both inside and outside of prison is important to prisoners with palliative and end of life care needs, inmate hospice volunteers are able to build and maintain close relationships with the prisoners they care for and the conflicting priorities of care and custody can have a negative impact on the delivery of palliative and end of life care in prisons.

Conclusions The key findings are: relationships are important to prisoners at the end of life, inmate hospice volunteers can build close bonds with the prisoners in their care and the prison environment and regime conflicts with best practices in palliative and end of life care. Directions for future research are also identified.

PROSPERO registration number PROSPERO ID: CRD42019118737. Registered January 2019.

Strengths and limitations of this study

- A rapid review synthesising the results of 23 primary research articles, from six databases spanning healthcare, the social sciences and criminology.
- The volume of research since the most recent systematic review has increased considerably, and has expanded by location.
- Rapid review methodology means that there may be grey literature and literature in other databases which was not retrieved.
- Limiting the timescale to 2014 to 2018 meant that a number of primary research articles pre-2014 were not included.

INTRODUCTION

The global prison population is ageing.[1–4] In the USA, almost 20% of the prison population is currently older than 50.[5] In France, the proportion of over 50s in prison grew from 4.5% in 1980, to 11.2% of the prison population in 2013.[6] In 2002, 7% of prisoners in England and Wales were older than 50; by 2018 this group accounted for 16% of the prison population.[7] The age profile of prisoners in Scotland is also following a similar pattern.[7] Prisoners also suffer poorer health than the general population, with certain cancers, blood-borne viruses and mental health conditions[8 9] being more prevalent in the prison population. This combination of poor prisoner health and the ageing of the prison population creates the likelihood of an increased demand for palliative and end of life care in prisons.

In some countries, policy and guidelines have been developed in order to set standards for the provision of palliative care to this population. In the USA, the National Hospice and Palliative Care Organization mandate that all prison hospices should achieve standards similar to those which would be expected in the community.[10] In the UK, drivers such as the Dying Well in Custody Charter[11] and Her Majesty's Inspectorate for Prisons Scotland standard for health and well-being[12] state that people in prison should have access to palliative care services equitable to those available

outside of prison. Yet the approaches taken to provide care to this population are varied, from the 'in-house' prison hospice model common in the USA, to the UK's palliative care 'in-reach' model, which sees specialist palliative care providers such as hospices supporting prisons to care for dying prisoners.[13]

This rapid review was undertaken as part of a larger project which is ongoing in Scotland, which aims to make recommendations for the future provision of palliative and end of life care for the prison population. The purpose of this rapid review is to provide a timely synthesis of recent research on palliative and end of life care in prisons. A number of literature reviews employing a range of methods[1 13–17] have been conducted in recent years, and have shown that research in this area is beginning to grow. The most recent systematic review by Wion and Loeb[1] reviewed literature up to mid-2014, therefore this review will only include literature from 2014 onwards.

Aims and research questions

The overall aim of this review is to explore current practice in relation to palliative and end of life care in prisons, and to make recommendations for its future provision. This will be achieved by answering the following four questions:

1. What is the current practice in relation to palliative and end of life care from the perspective of prisoners, their families, prison officers and prison healthcare staff?
2. What are the barriers and facilitators to the provision of palliative and end of life care in prisons?
3. How can hospices support prisons to provide palliative and end of life care?
4. What recommendations can be made for the future provision of palliative and end of life care in prisons?

METHODS

This review employed rapid review methodology. This can be described as an approach to knowledge synthesis which simplifies or omits elements from traditional systematic review methodology, in order to produce more timely results.[18] The review was registered on PROSPERO in January 2019.[19] The protocol was updated in March 2019 to reflect a change in quality appraisal tool, and an extension of the timescale for completion. The review is reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines,[20] and a PRISMA checklist can be found in online supplementary appendix 1.

Eligibility criteria

The review included primary research studies related to palliative and end of life care in prisons. Studies reporting qualitative or quantitative results were both included. Systematic or literature reviews, letters, conference abstracts, book chapters, theses and anecdotal accounts were excluded from the review. Articles were only retrieved from 2014 onwards, as preliminary searches revealed that a 2016 systematic review[1] of the same subject had included articles up to mid-2014. Limiting the date-range and only consulting published peer-reviewed literature is a common feature of rapid review methodology.[18]

Literature search

Six major databases spanning health, the social sciences and criminology (ASSIA, CINAHL, Embase, MEDLINE, National Criminal Justice Reference Service abstracts and Scopus) were searched. Searches were conducted in early January 2019, and covered from January 2014 to December 2018. Initial scoping searches were refined before being peer reviewed by Paul Cannon, a University of Glasgow librarian. The final searches were conducted by one author (CMP). The final search strategy employed a combination of subject headings and keyword title/abstract searches. The key terms which were searched across all databases were *palliative, hospice, hospices, end of life, terminal, prison, prisons, prisoners, jail, jails, incarcerated* and *incarceration*. Additional terms were employed dependant on the method by which databases were indexed (eg, CINAHL: Medical Subject Headings). The following is an exhaustive list of the additional terms employed: *imprisonment, remand prisoners, maximum security prisoners, imprisoned men, long-term prisoners, life imprisonment, correctional facilities, correctional health nursing, correctional facilities personnel, correctional health services, hospice patients, hospice care, hospice and palliative nursing*. An example search strategy can be found in online supplementary appendix 2.

Screening

The initial searches yielded 411 articles. After removal of duplicates, 219 articles remained. Titles and abstracts were screened by one author (CMP) against the predefined criteria listed above, resulting in the exclusion of a further 189 articles. The same author then read the remaining 30 articles in full, and in discussion and subject to agreement with the second author (BMJ), excluded a further seven articles, leaving the final number included in the synthesis at 23. Figure 1 is a PRISMA flow diagram outlining this process.

Data extraction

Data extraction tools were piloted alongside the initial search strategies. The final tool was developed through discussion between both authors, and was designed to capture the following information: author, year, country, design, aim, setting, sample/population, methods, key findings and conclusions.

Quality appraisal

Both authors independently scored the final 23 articles using the Qualsyst tool by Kmet *et al*.[21] Initial scoping of the literature indicated that a significant amount of qualitative research with a reasonable degree of methodological diversity would be included in the review. The reliability of applying a structured approach to the appraisal of a broad range of studies employing qualitative methods has been questioned,[21 22] yet allowing for

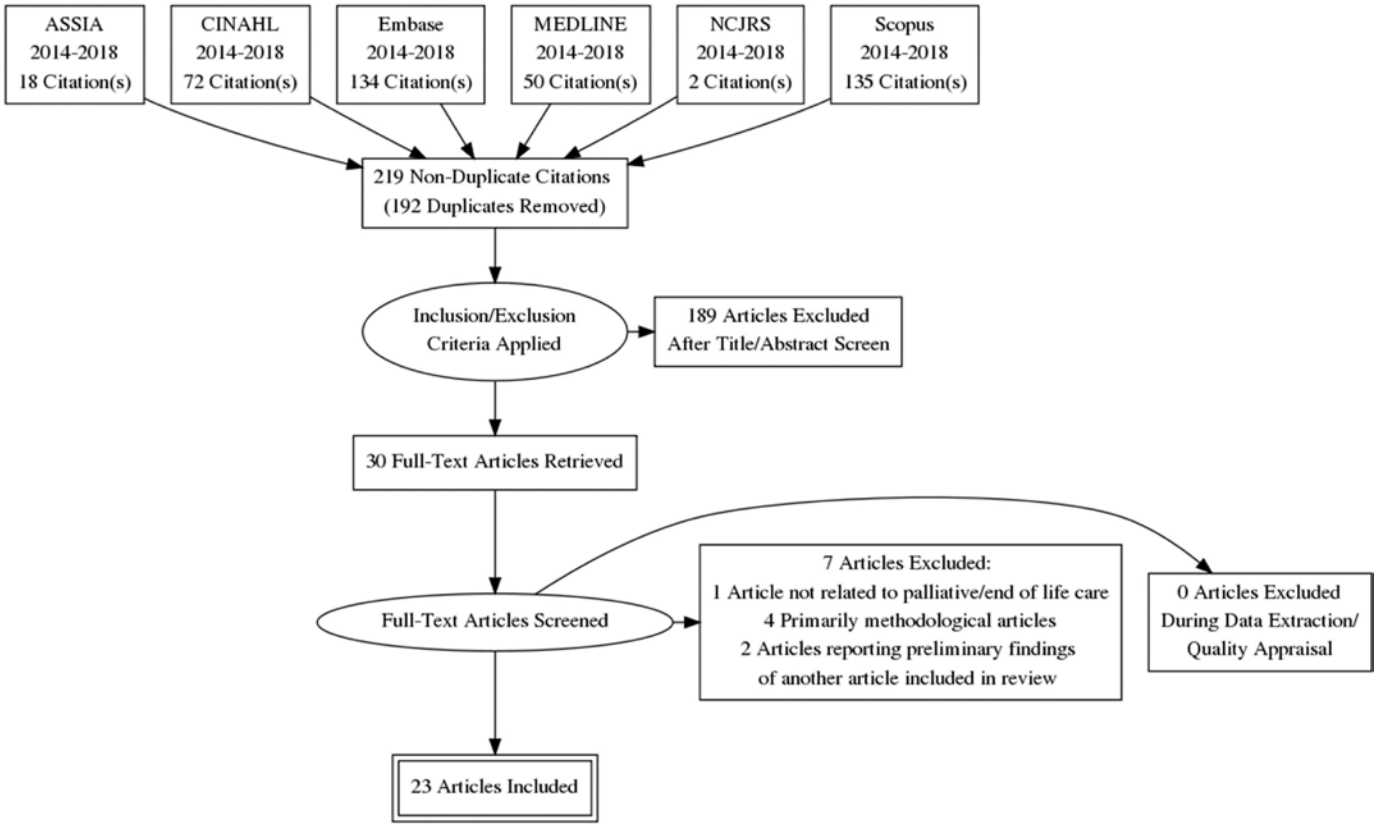

Figure 1 Prisma flow diagram.

distinctions to be made between the validity of studies and the strength of conclusions is an integral part of the systematic review process.[20] In addition, the small number of studies which employed quantitative methods were also methodologically diverse. The Qualsyst tool has been designed to assess the internal validity of a diverse range of study designs.[21] The validated tool has been primarily adopted in systematic reviews where studies employing a wide range of methods are to be included. The decision was taken not to exclude any studies based on their quality scores, due to this diversity.

The qualitative and quantitative components of the Qualsyst tool can be found in tables 1 and 2. Papers are scored 2, 1 or 0 for each question dependent on whether they satisfy, partially satisfy or do not satisfy the specified outcome. In the quantitative tool, 'not applicable' can also be selected for some questions. The total score is divided by the total possible score (20 for the qualitative tool and 18 to 28 dependent on number of 'not applicable' selected for the quantitative tool) and multiplied by 100 to provide a summary quality score, expressed as a percentage. Aggregate summary quality scores (SQS)

Table 1 Qualsyst qualitative scoring tool

	Questions for qualitative studies	Yes (2)	Partial (1)	No (0)
1	Question/objective sufficiently described?			
2	Study design evident and appropriate?			
3	Context for the study clear?			
4	Connection to a theoretical framework/wider body of knowledge?			
5	Sampling strategy described, relevant and justified?			
6	Data collection methods clearly described and systematic?			
7	Data analysis clearly described and systematic?			
8	Use of verification procedure(s) to establish credibility?			
9	Conclusions supported by the results?			
10	Reflexivity of the account?			

Table 2 Qualsyst quantitative scoring tool

	Questions for quantitative studies	Yes (2)	Partial (1)	No (0)	N/A
1	Question/objective sufficiently described?				
2	Study design evident and appropriate?				
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytical methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				
14	Conclusions supported by the results?				

were calculated by adding the two authors independent scores and dividing by 2. The aggregate SQS can be found in the article summaries in tables 3 and 4. There is a lack of consensus on the presentation of Qualsyst scores in systematic reviews, with approaches including the categorisation of studies by their score[23 24] (such as high quality, moderate quality, low quality), presentation of a simple percentage score[25 26] or the presentation of scores aggregated at the level of individual findings.[27] Given this lack of consensus, this review will present scores for both the included studies and the individual findings. Higher scores indicate a greater degree of methodological robustness.

Data analysis

Completed data extraction forms were imported into the qualitative data analysis system NVivo 12. The findings from the studies were then subject to a thematic analysis as outlined by Braun and Clarke.[28] In the context of this particular review, the analysis involved the following phases:

1. Becoming familiar with the data by reading and re-reading both the original studies and the completed data extraction forms.
2. Generating initial codes, using an inductive line-by-line coding approach.
3. Searching for themes and organising initial codes under these common themes.
4. Reviewing themes using a deductive approach to ensure that they provide an answer to the research questions.
5. Defining and naming themes in a way that ensured they were representative of the data.
6. Reporting the results in a narrative synthesis, providing an answer to each of the research questions.

As part of this approach, a thematic map was developed and refined (figure 2), in order to illustrate the major themes and their constituent subthemes. This method of data analysis allowed for the narrative synthesis of the results, with the major themes being represented by three of the original research questions. The fourth question is addressed in the discussion section.

Patient and public involvement

An advisory group of prisoners at one Scottish prison were involved in aspects of the design of the overall project of which this rapid review is one part. Meetings with the group helped to inform approaches to data collection in other parts of the study, and to develop more effective ways of communicating with the population. The group will also be involved in the dissemination of the overall study, which will include the rapid review.

RESULTS

Overview of included studies

The review identified 23 articles, 16 reporting qualitative methods[2 3 29–42] (table 3), six reporting quantitative methods[8 9 43–46] (table 4) and one reporting mixed methods[4] (table 3). Methodological diversity was high across all groups. Two qualitative studies only reported their methodological approach as 'qualitative'.[2 40] Thirteen articles reported findings from six studies based in the USA,[8 9 29–33 36 39–43] four articles reported findings from three studies based in the UK,[4 35 38 45] three articles reported findings from two studies based in Switzerland,[3 34 37] two

Table 3 Qualitative and mixed methods studies

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Chassagne *et al*[2] (2017) France	Prisoners requiring palliative and end of life care (n=14) and those around them	Qualitative (unspecified)/ interviews	To highlight the realities regarding inmates at the end of life in France	▶ Themes: – The limits of palliative and supportive care in prison – The boundary between inmate and patient in UHSI (a high-security ward for inmates based in a local hospital). ▶ The environment and equipment limit the ability to deliver palliative care in prisons. ▶ Conflicting priorities between care and custody in the UHSI also impact on care delivery.	**Strengths:** Evident and appropriate design, study context clear, sampling appropriate and well described, well supported conclusions **Limitations:** Limited information on data collection and analysis, no verification procedures described, limited information on reflexivity **Quality score**: 63%
Cloyes *et al*[31] (2014) USA	Louisiana inmate hospice volunteers who responded to a survey (n=75)	Ethnographic grounded theory/ surveys	To explore the beliefs and attitudes of inmate hospice volunteers, including motivations and the meaning of hospice to them	▶ Themes: – *Transforming personal identity* – *Expressing true self* – *Personal redemption* – *Doing God's work* – *Living the golden rule* – *Witnessing and legacy vs passing without notice* – *Stepping up* – *Paying it forward by giving back* – *Collective identity through common humanity*. ▶ Inmate hospice volunteers view hospice as a transformative experience, which changes them for the better.	**Strengths:** Question sufficiently described, study context clear, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial connection to theoretical framework, limited information on reflexivity **Quality score:** 85%
Cloyes *et al*[29] (2016) USA	Louisiana State Penitentiary prisoners, inmate hospice volunteers, healthcare staff and corrections officers (n=43)	Ethnographic case study/ interviews and observations	To describe factors essential to sustaining the prison hospice, from prisoner, corrections officer, healthcare staff, and inmate volunteer perspectives	▶ Themes: – *Patient centred care* – *The inmate hospice volunteer model* – *Safety and security* – *Shared values* – *Teamwork* ▶ The importance of healthcare staff, corrections officers, volunteers and prisoners working together is emphasised. ▶ The inmate hospice volunteer model is described as being essential to the success of the hospice.	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial connection to theoretical framework, limited information on reflexivity **Quality score:** 85%
Cloyes *et al*[30] (2017) USA	Louisiana State Penitentiary prisoners, inmate hospice volunteers, healthcare staff and corrections officers (n=43)	Ethnographic case study/ interviews and observations	To describe how inmate hospice volunteers learn hospice care	▶ Themes: – *Formal training and education/practical experience at the bedside* – *Formal and informal peer mentorship* – *Interactions with nursing and corrections staff* ▶ Structured training, bedside experience, peer mentorship and support from nurses and corrections officers enable volunteers to become an invaluable part of the hospice team.	**Strengths:** Study context clear, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial connection to theoretical framework, limited information on reflexivity **Quality score:** 80%

Continued

Table 3 Continued

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Depner *et al*[32] (2017) USA	Inmate hospice volunteers (n=22) from a maximum security prison in the north-eastern USA	Consensual qualitative research/ interviews	To explore the phenomenological perspective of inmates participating in inmate facilitated hospice care with regard to meaning and purpose in life, attitudes on death and dying, and the personal impact of participation	▶ Themes: – *Confronting death and dying* – *Personal growth and transformation* ▶ Varied thoughts on death and dying and discussion of the impact exposure to death has on inmate hospice volunteers. ▶ Volunteers reflect on the impact their role has had on them, with discussion of personal growth and transformation, conceptualised as posttraumatic growth.	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, connected to theoretical framework, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions, reflexivity present **Limitations:** limited information on sampling **Quality score:** 95%
Depner *et al* [33] (2018) USA	Inmate hospice volunteers (n=22) from a maximum security prison in the north-eastern USA	Consensual qualitative research/ interviews	To (a) describe a prison-based end of life programme utilising inmate peer caregivers, (b) identify inmate caregiver motivations for participation and (c) analyse the role of building trust and meaningful relationships within the correctional end of life care setting.	▶ Themes: – *Programme description* – *Motivation* – *Connecting with others* ▶ Hospice programme was generally well regarded in the prison. ▶ There are numerous drivers for becoming a peer caregiver, including the idea of 'giving something back' or making amends for past wrongs. ▶ Connections are important, not only between carer and patient, but with family, friends and other inmates.	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions, reflexivity present **Limitations:** Partial connection to theoretical framework **Quality score:** 98%
Handtke & Wangmo[3] (2014) Switzerland	Older inmates in Swiss prisons (n=35)	Theoretical (Allmark's concept of 'death without indignities')/ interviews	To investigate elderly prisoners' attitudes towards death and dying	▶ Themes: – *Attitudes towards death and dying* – *Experiences with other prisoners deaths and accounts of personal life-threatening situations* – *Suicide and suicidal thoughts* – *Realities of end of life services available in prison* – *Importance of maintaining relationships with family and friends at the end of life* – *Wishes to die outside prison* ▶ Varied attitudes towards death and dying shaped by experiences of death. ▶ Palliative and end of life care service provision viewed as poor. ▶ Maintaining links to family is seen as important, and most prisoners were focussed on surviving their sentence to die outside.	**Strengths:** Study context clear, connected to theoretical framework, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial description of question and overall design, limited information on reflexivity **Quality score:** 85%
Handtke *et al*[34] (2017) Switzerland	Older inmates in Swiss prisons (n=35)	Theoretical (Garland's depiction of the criminology of the self and the criminology of the other)/ interviews	To (a) present opinions of older prisoners in Switzerland on early release on compassionate grounds, (b) to frame arguments against Garland's (1996) two criminologies of self and other, and (c) propose a middle way based on Garland's welfarist criminology and European human rights	▶ Themes: – *Change in circumstances due to illness or old age* – *Shared humanity* – *A clash of beliefs and reality* ▶ The prison environment is unsuitable for elderly prisoners, who are also less dangerous due to their age. ▶ People should be afforded the dignity to either be released or cared for properly in prison. ▶ While prisoners are optimistic about being released when they are nearing death, their past experiences are in conflict with this belief.	**Strengths:** Question sufficiently described, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Limited information provided on design and the context for the study, as well as reflexivity **Quality score:** 83%

Continued

Table 3 Continued

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Lillie *et al*[35] (2018) UK	Health professionals from a specialist palliative care provider (n=10)	Pilot study/ focus group	To understand the challenges faced by community palliative care providers when caring for those in custody	▶ Themes: – *Inpatients under prison, probation or police supervision altered the dynamics of care provision* – *Prisoners as relatives* – *Encountering offending behaviour in the home* ▶ Only the first theme is relevant to this review. ▶ The concept of restraints being used in the hospice setting was discussed. It was acknowledged that it did not occur often, but was a negative experience for all concerned when it did. It was challenging to connect with the patient in this environment.	**Strengths:** Question sufficiently described, study context clear, well-supported conclusions **Limitations:** Limited information on design, sampling, data analysis and reflexivity, not linked to theoretical framework, very limited information on data collection and verification procedures **Quality score:** 55%
Loeb *et al*[36] (2014) USA	Current and potential users of palliative and end of life care services in a mid-Atlantic USA state (n=21)	Descriptive/ interviews	To examine the values, beliefs, and perceptions held by current and potential future consumers of end of life care in prisons to highlight the facilitators and barriers to providing compassionate care for those dying in prison.	▶ Themes: ▶ *Seeking human interaction* ▶ *Accessing material resources* ▶ *Obtaining compassionate care* ▶ *Seeking equitable care* ▶ *Addressing physiological needs* ▶ *Facing death*. ▶ The prison environment and resources present significant challenges to accessing care that is equitable to that available outside, or even to meeting basic needs. ▶ Interacting with other people, and inmate volunteers were seen as important. ▶ Themes:	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Limited information provided on reflexivity. **Quality score:** 88%
Marti *et al*[37] (2017) Switzerland	Prisoners, corrections officers, healthcare staff, representatives of prison authorities and a prison chaplain instructor (n=62)	Ethnographic/ multimethod (interviews, observations, case study reconstructions)	To answer the following questions: (1) What are the institutional logics of the prison system and how are these logics challenged by the logic of long-term geriatric and EOL care? (2) How do these institutional logics shape everyday practices of prison officers and how do they also question, resist, and transform them in their daily work activities?	Themes: ▶ Thornton and Ocasio's (1999, 2008) 'institutional logics' perspective applied: – *Institutional Logics and Daily Practice: INTERinstitutional cases:* care and custody must be balanced, some corrections officers exercise discretion in order to do this – *Institutional Logics and Daily Practice: INTRAinstitutional cases:* the type of care delivered in prison is transitioning from curative to palliative. Corrections staff again acting outside role to meet the needs of prisoners.	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, connected to theoretical framework, well-supported conclusions **Limitations:** Partial information on sampling, data collection and data analysis, limited information on verification procedures and reflexivity **Quality score:** 65%
Peacock *et al*[38] (2017) UK	Mixed sample of prisoners, prison officers, healthcare staff and others involved in prison service (n=62)	Action research/ interviews, focus groups and observations	To discuss the concept of 'jail craft'	▶ Themes: – *Jail craft – an introduction* – *Cost of benchmarking: resources and frustrations* – *Prison officers and end of life care* ▶ Discusses the concept of 'jail craft': a protective, nostalgic discourse adopted by prison officers in the face of increasing pressures on the service, both in relation to end of life care, and other political drivers.	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, connected to theoretical framework, data collection appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Limited information on sampling strategy and reflexivity **Quality score:** 78%

Continued

Table 3 Continued

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Penrod *et al* [39] (2014) USA	Central administrators for a state department of corrections (n=12)	Descriptive/ interviews	To describe perspectives of end of life care held by prison administrators in a state prison system to reveal challenges to changing practice in this area.	▶ Themes: – *Centralised policy vs local prison culture* – *Treatment vs security focus* – *Case-by-case vs system-wide perspectives* – *Needs vs public sentiment* – *Budget neutral approaches vs demands on the system* – *Inmate vs staff service* ▶ Many challenges to be overcome when changing practice, including the conflict of care vs custody. ▶ Acknowledgement of the grief of prisoners, carers and correctional staff exposed to death in prison.	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial information on sampling strategy and limited information on reflexivity **Quality score:** 83%
Sanders & Stensland [40] (2018) USA	Prisoners nearing end of life in mid-western USA, who took part in an anticipatory care planning (ACP) session (n=20)	Qualitative (unspecified)/ observation of ACP session	To report on the inmate experience of approaching death in prison	▶ Themes: – *Losing a piece of everything* – *Not sure what to feel* – *Where will I die?* – *Finding purpose in the midst of purposelessness* – *Preparing for the inevitable* ▶ Inmates experienced a range of emotions and reactions to approaching death. ▶ Many felt strongly that they did not want to die in prison or be buried on prison property. ▶ Importance was placed on things that provide meaning, such as religion, family, prison jobs and small things like TV.	**Strengths:** Question sufficiently described, study context clear, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial information on design, connection to theoretical framework, and reflexivity **Quality score:** 83%
Sanders *et al* [41] (2018) USA	Prisoners nearing end of life in mid-western USA, who took part in an ACP session (n=20)	Theoretical (Bandura's agentic perspective)/ observation of ACP session	To develop insight about the opportunities and needs of offenders in directing the end of life care they receive and the dying process that they ultimately experience, which an agentic perspective facilitates.	▶ Discussed with reference to Bandura's agentic perspective (2006). ▶ Themes: – *What works best for me* – *Feeling blessed* – *Decisions in the shadows of the past* – *What is really going on?* – *Can anyone be trusted?* – *Turning agency over to someone else* ▶ Some aspects of ACP planning enacted agency and made prisoners feel positive. Others were suspicious. ▶ Despite all wishing to have a proxy decision maker for when they became too unwell, only a small amount could identify anyone outside of prison to adopt this role.	**Strengths:** Question sufficiently described, study context clear, connected to theoretical framework, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial information on overall design and reflexivity **Quality score:** 90%

Continued

Table 3 Continued

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Supiano *et al* [42] (2014) USA	All hospice volunteers in Louisiana State Penitentiary (n=36)	Descriptive/ interviews	To answer the following: (1) How do inmates recall death experiences that occurred prior to their entry into the hospice volunteer role? (2) How do volunteers describe the meaning of these deaths and any impact on their volunteer work? (3) How do volunteers describe the experience of caring for dying inmates? (4) Are these deaths associated with grief in the volunteers, and how is this grief addressed?	▶ Themes: – *Experience with death* – *Death of patients in hospice care* – *The grief of hospice volunteers* ▶ Volunteers had varied responses to death, but perceived their role as essential in supporting the dying in the hospice. ▶ They were confronted by their own mortality when patients died. ▶ They experienced profound grief, and coped with it through various mechanisms, including spirituality, throwing themselves into work and peer support.	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, sampling appropriate and well described, data collection appropriate and well described, data analysis appropriate and well described, verification procedures present, well-supported conclusions **Limitations:** Partial acknowledgement of reflexivity **Quality score:** 90%
Turner *et al* [4] (2018) UK	Interviews with mixed correctional and healthcare staff and prisoners (n=64) and survey of elderly prisoners (n=127)	Mixed methods action research/ survey and interviews	To understand the social processes at work in a prison setting and how they impact on the provision of health and social care for ageing and dying prisoners	▶ Themes: – *Frailty and vulnerability* – *Prison environment and resources* ▶ The prison environment is not suited to the increasingly large population of elderly prisoners, many of whom are fearful of the younger prisoners. ▶ Survey findings: – Total population of 202 prisoners older than 55 were surveyed. 62.9% responded (n=127). – Mean age 65, oldest prisoner 91. – 75% are in prison for the first time. – 28.4% rate their health as very poor. – 22% have five or more health conditions. – 55.9% have three or more health conditions. – 91% have at least one condition. – 49.6% are on at least five drugs, 89% are on at least 1. – 26% can't walk 100 m. – 18.9% can't manage stairs. – 30.7% had a fall within the last 2 years. – 72% older prisoners would like to be housed separately to younger prisoners	**Strengths:** Question sufficiently described, evident and appropriate design, study context clear, data collection appropriate and well described, well supported conclusions **Limitations:** Limited information on verification procedures and reflexivity **Quality score:** 73%

Table 4 Quantitative studies

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Chari *et al* [43] (2016) USA	Representatives from each of the 50 state department of corrections (n=45)	Cross-sectional national telephone survey	To present selected findings on the provision of healthcare in US state prisons	▶ 45 of 50 States responded ▶ 35 States provide hospice care exclusively on-site ▶ Of this 35 to 12 have specific or reserved hospice beds ▶ Of this 12 to 6 are joint hospice and long-term care units ▶ Nine provide hospice care both on-site and off-site ▶ 'Most' state that off-site care is rarely used	**Strengths:** Question sufficiently described, evident and appropriate design, subject group characteristics/variables described sufficiently, analytical methods justified and appropriate, well supported conclusions **Limitations:** The appropriateness of the visual representation of some results is not clear **Quality score**: 93%
Cloyes *et al*[8] (2015) USA	All patients admitted to the Louisiana State Penitentiary (LSP) hospice programme from 01/2004 to 05/2012 (n=79)	Comparative descriptive study, retrospective	To document characteristics of population of prison hospice patients, and to describe differences between this population and the general community	▶ Average LSP patient age at time of death: 56 (SD=9.72, range 29–75) ▶ Less than 16% community-hospice patients were aged 64 or younger on admission. 83% LSP patients were under 64. ▶ Average time incarcerated before admission to hospice was 14.6 years ▶ 1/3 LSP patients have two or more major illnesses prior to hospice ▶ 41% have HIV or hepatitis ▶ 60% of community admissions to hospice are for non-cancerous diseases. Only 6% LSP admissions are for non-cancer. ▶ Median LSP hospice stay is 40 days compared with 19 in the community ▶ 90% of LSP patients received opioids during the final 72hours of life ▶ Prison hospice patients had significantly less distressing symptoms (breathlessness, delirium, agitation) at the end of life than community based patients.	**Strengths:** Question sufficiently described, evident and appropriate design, subject selection/information source appropriate, subject group characteristics/variables described sufficiently, outcome well defined and robust to bias, detailed results, well supported conclusions **Limitations:** Partial information on how comparison group data obtained **Quality score:** 93%
Jadhao *et al*[44] (2015) India	All deaths in custody from natural causes which were brought to a single hospital in India for autopsy between 01/2008 and 12/2013 (n=96)	Retrospective descriptive study	To examine mortality patterns in custodial deaths in a part of India	▶ 118 deaths in custody. 96 (81.35%) of these were of natural causes ▶ Of the 96, 87 (90.62%) were male, nine (9.38%) were female ▶ Ischaemic heart disease most common cause of death (23.95%) ▶ Pneumonia (21.87%) ▶ Tuberculosis (21.87%)	**Strengths:** Minimal methods reported - difficult to assess strengths **Limitations:** Partial reporting of question, design, subject selection and characteristics, results and conclusions. Cannot discount misclassification bias with limited information provided on how outcome (cause of death) was measured. No information on how data were extracted and analysed. **Quality score:** 38%

Continued

Table 4 Continued

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Papadopoulos & Lay[45] (2016) UK	Nurses who have worked in a prison in England or Wales within the previous 2 years (n=31)	Online survey	To investigate views of current and former (<2 years) prison nurses with regard to end of life care being provided in UK prisons	▶ 21/31 (68%) reported having some form of palliative and end of life care experience; for most this was due to a previous role as a community nurse or through a short course from a hospice ▶ 12 stated their prison had a written palliative care policy, four stated their prison did not, seven were unsure ▶ 23/31 provided information on their prison's facilities: – 52.2% stated their prison had a hospital wing – 43.5% stated they had at least one nurse with palliative care training – 30.4% had prison volunteer carers or 'buddies' allocated to dying prisoners – 13.0% had facilities for families of dying prisoners ▶ Barriers to end of life care included environmental barriers (no hospital wing, all single cells), regime barriers (perceived inflexibility, fixed visiting times) and security barriers (frequent lock-downs, failure to appreciate the reduced risk of dying prisoners causing harm.) ▶ Examples of good practice include: access to specialist palliative care and specialist equipment, supportive policies (eg, named nurse, 24 hours unlocking for end of life) support (peer carers, custodial staff) and better access to families	**Strengths:** Sufficient participant information, well supported conclusions **Limitations:** Limited depth of information on design and results. Risk of response bias due to small sample and potential for respondents to be from same establishment: cannot generalise about establishments and facilities as a result. **Quality score:** 57%
Pazart *et al*[46] (2018) France	All healthcare units for prisoners in France (n=190). Prison population 66 698	Prospective national survey	To assess the number and characteristics of prisoners requiring palliative care in French prisons	▶ n=60 palliative care situations were identified. 10 were excluded for various reasons including consent, incomplete responses and life expectancy >1 year. Sample=50. ▶ The majority of these patients were male (47:3) which is representative of the prison population as a whole ▶ The estimated annual prevalence of sick prisoners requiring palliative care is 15.2 per 10 000 (CI 12.5 to 18.3). This number is twice as high as it would be for an equivalent patient in the community, or equivalent to someone 10 years their senior. ▶ 33/50 requested early release on compassionate grounds. ▶ 16/33 received a positive answer to this request ▶ It is estimated that a further 12/50 would also have been eligible for early release on compassionate grounds, but did not request it.	**Strengths:** Question sufficiently described, evident and appropriate design, subject selection/information source appropriate, subject group characteristics/variables described sufficiently, outcome well defined and robust to bias, sample size appropriate, analytical methods justified and appropriate, variance reported for main results, detailed results, well supported conclusions **Limitations:** More detail on physician classification/diagnosis of prisoners could improve **Quality score:** 95%

Continued

Table 4 Continued

Citation and country	Participants	Design	Aim	Key findings	Key methodological strengths and limitations; quality score
Rothman *et al*[9] (2018) USA	All state hospital decedents from 2009 to 2013 (n=370 831)	Cross-sectional, comparative study	To compare incarcerated and non-incarcerated decedents in California	▲ 370 831 hospital decedents. 745 incarcerated, 370 086 non-incarcerated ▲ Incarcerated decedents were more often male (93% vs 51% p<0.05) and younger (55 vs 73 years old, p<0.05) ▲▲ Fewer had advanced care plan (23% vs 36% p<0.05) ▲▲ Between 2001 and 2013, number of non-incarcerated decedents over 55 stayed at 80%, while it grew from 33% to 46%, with a peak of 55% in 2010 for incarcerated ▲ Incarcerated decedents were more likely to have the following diagnoses on admission to hospital: cancer (10.2% vs 6.4%), liver disease (3.5% vs 1.4%), or mental health conditions (2.6% vs 1.1%), all p<0.05 ▲ On admission, incarcerated decedents were almost five times as likely to have HIV or AIDS (1.9% vs 0.4%) and 10 times as likely to have hepatitis (4.2% vs 0.4%) ▲ Causes of death which were more common in incarcerated decedents included viral hepatitis (10.6% vs 1.0%), suicide (3.1% vs 0.3%), drug overdose (3.4% vs 0.4%), and homicide (0.9% vs 0.3%) all p<0.5.	**Strengths:** Question sufficiently described, evident and appropriate design, subject selection/information source appropriate, outcome well defined and robust to bias, sample size appropriate, analytical methods justified and appropriate, detailed results, well supported conclusions **Limitations:** Subject group description limited by lack of recorded data on incarcerated decedents. **Quality score**: 80%

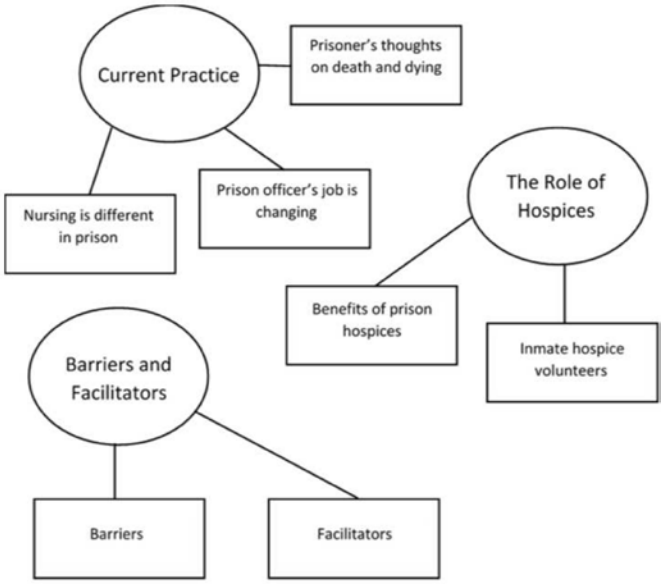

Figure 2 Thematic map.

articles reported findings from one study in France[2 46] and one article reported findings from a study in India.[44] The articles reported on a broad range of areas, including prison healthcare facilities,[43 45] the health of dying prisoners and causes of death,[8 9 44 46] elderly and dying prisoners views on issues related to palliative and end of life care in prisons[3 4 34 36 40] and inmate volunteer caregivers.[30–33 42] Of the 19 studies which sampled prisoners (or their case records),[2–4 8 9 29–34 36–38 40–42 44 46] 12 dealt exclusively with male prisoners,[4 8 29 30 32 33 36–38 40–42] and seven with male and female prisoners.[2 3 9 31 34 44 46]

Quality of included studies

The mean SQS of all included studies was 80%, with a range of 38% to 98%. The mean SQS of qualitative and mixed methods studies was 81% (range 55% to 98%) and the mean SQS of quantitative studies was 76% (range 38% to 95%). Partial or limited information on reflexivity and partial connection to a theoretical framework accounted for most points deducted on the qualitative tool across the 17 papers scored using it. Variety and the smaller number (n=6) of quantitative papers meant that it was not possible to generalise about the main causes for deducted points on the quantitative tool.

Narrative synthesis

A summary of the top 10 findings by prevalence can be found in table 5.

What is current practice in relation to palliative and end of life care from the perspective of prisoners, their families, prison officers and prison healthcare staff?

Prisoners experience comparatively high levels of morbidity[4 8 9 44 46] (median SQS=80%; range 38% to 95%, n=5 studies). Pazart *et al* noted in their prospective national survey that the estimated annual prevalence of prisoners requiring end of life care in France was 15.2 per 10 000 (CI 12.5 to 18.3), a number twice as high as

Table 5 Top 10 findings by prevalence and summary quality scores (SQS)

Finding	SQS		
	Median	Range	Studies (n)
1. Fostering relationships with people both inside and outside of prison is important to prisoners with palliative and end of life care needs[2 3 29–33 36 40 41 45]	85%	57%–98%	11
2. Inmate hospice volunteers are able to build and maintain close relationships with the prisoners they care for[29–33 36 41]	88%	80%–98%	7
3. The conflicting priorities of care and custody can have a negative impact on the delivery of palliative and end of life care in prisons[2 29 30 35 37 39 45]	68%	55%–85%	7
4. Maintaining family relationships is important to prisoners at the end of life[2 3 33 36 40 41]	87%	63%–98%	6
5. Nursing in prison requires a set of skills unique to the custodial environment[2 4 29 32 35 36]	79%	55%–95%	6
6. The physical environment of the prison can present a barrier to the delivery of palliative and end of life care[2–4 34 36 45]	78%	50%–90%	6
7. Inmate hospice volunteers experience grief as a result of their role[30–32 39 42]	85%	80%–95%	5
8. Recognition of a shared humanity between individuals can encourage better attitudes to palliative and end of life care delivery in prison, across disciplines[29 30 33 34 38]	83%	78%–98%	5
9. Prisoners who may die in prison have a strong desire to either survive their sentence, or to be released early on compassionate grounds[3 4 34 40 41]	83%	73%–90%	5
10. Prisoners have poorer health than the general population[4 8 9 44 46]	80%	38%–95%	5

the expected age/sex standardised equivalent in the general community, or similar to someone 10 years their senior.[46] Rothman *et al* compared all incarcerated and non-incarcerated decedents in the state of California, finding higher rates of cancer (10.2% vs 6.4%), liver disease (3.5% vs 1.4%), mental health conditions (2.6% vs 1.1%), HIV/AIDS (1.9% vs 0.4%) and hepatitis (4.2% vs 0.4%, all p<0.05) in the incarcerated decedents.[9] Cloyes *et al* placed the proportion of patents with HIV or hepatitis admitted to a long-running prison hospice over an 8.5 year period at 41%.[8]

Prisoners' general thoughts on death and dying were widely represented across the qualitative studies,[3 4 32 34 36 40–42] and were varied. Some were accepting of death as something inevitable and natural[3 32] (median SQS=90%; range 85% to 95%, n=2 studies), others found prolonged and frequent exposure to death in prison to be demoralising[36 40 42] (median SQS=88%; range 83% to 90%, n=3 studies). The perspective of prisoners' family members was considered in only one study,[2] although several studies cited the perceived importance of family relationships for prisoners at the end of life[2 3 33 36 40 41] (median SQS=87%; range 63% to 98%, n=6 studies).

Some studies noted that prison officers are under increasing pressure, and that their job is changing to meet the needs of the ageing prison population[36–39] (median SQS=81%; range 65% to 88%, n=4 studies). Marti *et al* detail how prison officers in Switzerland adapt to these changes by informally taking on new duties (such as applying eye ointment for an elderly prisoner) that would traditionally have been undertaken by healthcare staff.[37] However, some UK prison officers felt ill-prepared to undertake these additional duties, and argued that it was not part of their job[4 38] (median SQS=76%; range 73% to 78%, n=2 studies).

Current practice in relation to healthcare staff was characterised by the differences between caring for people in prison compared with caring for people outside prison. Nursing in prison involves negotiating a number of challenges unique to the prison nurse role, such as setting aside personal beliefs to care for those who have committed terrible crimes, supporting and overseeing inmate volunteers and managing potentially conflicting priorities with custodial staff[2 4 29 32 35 36] (median SQS=79%; range 55% to 95%, n=6 studies).

Even obtaining a simple pressure-relieving mattress was challenging due to the non-standard size of prison beds in one study.[4] There was limited information regarding the training and experience of prison nurses. Of the small number of UK prison nurses who responded to Papadopoulos and Lay's online survey, 68% stated that they had previous experience of palliative and end of life care, mostly due to either clinical experience in previous roles, or from attending a course.[45]

What are the barriers and facilitators to the provision of palliative and end of life care in prisons?

The barriers to palliative and end of life care in prison can largely be separated into two areas: physical barriers and ideological barriers.

The most commonly identified physical barrier is the prison environment itself[2–4 34 36 45] (median SQS=78%; range 57% to 88%, n=6 studies). Prisons are described as noisy,[4 34] cold[4 36] buildings where single cells, locked door

policies[45] and other environmental barriers prevent prisoners from accessing equitable care. In one UK survey of prisoners aged 55 and over, 26% said they couldn't walk 100 m, 18.9% said they could not manage stairs and 30.7% had fallen in the last 2 years.[4] Coupling these factors with an ageing prison estate could create significant potential for both injury and inequality. Some studies also noted that a lack of essential resources such as beds, linen and portable oxygen were creating barriers to effective palliative and end of life care[2 36 39] (median SQS=83%; range 63% to 88%, n=3 studies). Drug administration also poses a number of problems. In their US study, Loeb *et al* recorded contradictory views regarding the quality of pain relief given to prisoners at the end of life. However, they also highlighted the stigma that can impact on decisions about analgesia when an individual has been labelled as having a history of drug abuse, even when the individual has long since ceased to abuse drugs.[36] In contrast, Cloyes *et al*'s retrospective review of case notes found that 90% of patients who had attended the prison hospice in their study received opioid analgesics in the last 72 hours of life.[8] Yet even when adequate analgesia is prescribed, there are still barriers to the administration of medicines. Nurses in one study reported coming in to the prison overnight while not on shift, in order to assist in the administration of controlled drugs.[4] Two studies also cited the inflexibility of the prison regime with regard to things like visitation as preventing a high standard of palliative care delivery[3 45] (median SQS=71%; range 57% to 85%, n=2 studies).

Alongside these physical barriers, there are also ideological barriers to palliative and end of life care in prisons. Several studies highlighted the conflicting priorities of care and custody, and the way they could affect care[2 29 30 35 37 39 45] (median SQS=68%; range 55% to 85%, n=7 studies). Locked doors at the end of life,[2 45] and the use of handcuffs and restraints when offenders are attending community hospitals or hospices[35] are examples of how care and custody can clash. Inmate hospice volunteers require greater freedom of movement within their prisons in order to fulfil their role,[29] and this can also create friction. Public opinion was also perceived to be a barrier, in that any investment of money or effort in improving palliative and end of life care for prisoners would be viewed negatively[34 39] (median SQS=83%; range 83% to 83%, n=2 studies). Prisoners themselves also presented a barrier, as mistrust of the prison staff and the prison system in general can impact on the way they engage with services[2 41] (median SQS=73%; range 63% to 83%, n=2 studies).

The most common facilitator of good palliative and end of life care in prison was allowing for the fostering of close relationships, particularly with families and other inmates (including inmate hospice volunteers)[2 3 29–33 36 40 41 45] (median SQS=85%; range 57% to 98%, n=11 studies). Facilitating visits from families was seen as important[2 3 40 45] (median SQS=73%; range 57% to 85%, n=4 studies), although some prisoners had limited, strained or no contact with their real families[2 3 31 41] (median SQS=85%; range 63% to 90%, n=4 studies). Some prisoners view the prison in which they have been incarcerated in for the majority of their sentence as their home,[40] and the prisoners around them as a substitute family[31 33 41] (median SQS=90%; range 85% to 98%, n=3 studies). It is seen as important that a prisoner maintains contact with their both their biological family, and their substitute prison-family at the end of life.

Compassionate release from prison for those at the end of life is also a means by which prisoners can gain equitable access to palliative and end of life care. Many prisoners expressed a strong desire to be released before death, or to survive their sentence[3 4 34 40 41] (median SQS=83%; range 73% to 90%, n=5 studies). Prisoners were also perceived to be less dangerous as they became older[4 34 45] (median SQS=73%; range 57% to 83%, n=3 studies). However, Pazart *et al* found that of the 50 French prisoners with palliative care needs who were identified at the time of their national survey, only 33 requested compassionate release, and only 16 were granted it.[46] The authors also found that when they assessed the 50 patients against the criteria for compassionate release, there were a further 12 who it appeared would have been eligible, but did not submit a request.[46]

Access to specialist palliative care services was identified by both prisoners and clinicians as important (median SQS=70%, range 57% to 83%, n=2 studies). Handtke *et al*'s study from Switzerland makes mention of an outside hospice which is viewed by prisoners to be a dignified place of death,[34] while the UK prison nurses who responded to Papadopoulos and Lay's survey identified access to specialist palliative care services as a facilitator of good palliative care.[45] In countries where prisoners are escorted to hospices outside the prison by custodial officers, reasonable limitation of restraint measures may also improve care delivery. In their small UK pilot study, Lillie *et al* discussed the experiences of a specialist palliative care team encountering offenders in the community, and found that the use of restraints and the presence of a custodial officer impacted negatively on the dynamics of care provision.[35]

Person-centred care is also important at the end of life. When an individual's ability to exercise personal agency in their daily life is severely restricted, it is comprehensible that they may be keen to do so with regard to their death. Some placed importance on planning for the end of life[3 40 41] (median SQS=88%; range 83% to 90%, n=3 studies), including with regard to anticipatory care planning.

In their comparative study, Rothman *et al* found that incarcerated decedents were less likely to have an anticipatory care plan that non-incarcerated decedents (23% vs 36%, $p<0.05$).[9] Person-centred care was also described in the form of ensuring that the individual has access to small comforts that provide them with enjoyment or a sense of purpose, such as television, video games or special foods like ice cream[36 40 41] (median SQS=88%; range 83% to 90%, n=3 studies).

Shared values, shared humanity and teamwork are discussed in several studies when describing the positive approaches of healthcare staff, inmate volunteers and prison officers that contribute to the delivery of palliative and end of life care[29 30 33 34 38] (median SQS=83%; range 78% to 98%, n=5 studies). Examples are given of prison officers who are balancing security demands with a commitment to care[29 36 37] (median SQS=85%; range 65% to 88%, n=3 studies), and prioritising the individual over fixed rules, when it is appropriate. Inmate hospice volunteers are seen to be an essential part of this team, and will be discussed fully in the following section. Finally, it is recognised that the whole team and the prison as an institution must acknowledge deaths when they do happen, and ensure that the individual's death is marked in some way[3 31 32] (median SQS=85%; range 85% to 95%, n=3 studies).

How can hospices support prisons to provide palliative and end of life care?

There is a dearth of literature dealing with the role of off-site hospices in supporting prisons. Given that a large volume of the literature comes from the USA,[8 9 29–33 36 39–43] this is perhaps unsurprising. In their national telephone survey, Chari *et al* found that 35 of the 45 states who participated in the survey provided prison hospice care exclusively on-site, with nine of the remaining 10 providing hospice care mostly on-site as well.[43] The remaining one state did not respond to that question.

Prison hospices are advocated for in several studies[8 29 33 37] (median SQS=89%; range 65% to 98%, n=4 studies). However, a large proportion of the literature dealing with prison hospices is focussed primarily on inmate hospice volunteers, who are seen as being essential to the prison hospice model[29 36 39 45] (median SQS=84%; range 57% to 88%, n=4 studies).

Inmate volunteers are able to build and maintain very close relationships with the dying prisoner[29–33 36 41] (median SQS=88%; range 80% to 98%, n=7 studies). Cloyes *et al* suggest that the benefit of this relationship also extends to prison healthcare staff, as the dying prisoner may be more comfortable disclosing information to the volunteer, allowing them to act as a conduit for information between the two,[30] which could be particularly helpful in instances where a lack of trust in the prison system is presenting a barrier.

The benefits of inmate volunteers also extend to the effective functioning of the prison hospice. In their case study of one of the longest-running prison hospices in the USA, Cloyes *et al* identify a formal inmate volunteer programme as one of the key components of its success and longevity.[29] At this particular prison hospice, the volunteers learn their role through a combination of taught theory, practical bedside experience and peer mentorship,[30] resulting in highly skilled carers. In a separate US study, prison administrators praised hospice volunteers as being successful due to them being budget-neutral, which was viewed as essential to the success of any prison hospice.[39]

Perhaps the most unexpected benefit of the inmate hospice volunteer model, however, is the benefit it conveys to the volunteer themselves. There was a recognition that being a hospice volunteer was a transformative experience[31–33] (median SQS=95%; range 85% to 98%, n=3 studies), characterised by either personal growth and rehabilitation,[31 33] or by allowing the prisoner to reveal the caring person that they really were.[31] The inmate volunteers' understanding and perceptions of the hegemonic masculinity that pervades the prison system was also challenged by the experience of being a volunteer[30–32 42] (median SQS=88%; range 80% to 95%, n=4 studies). Men felt that it enabled them to be 'real men' by caring for others,[30] and provided some respite from the hypermasculine world they normally inhabited.[31] Volunteers experienced grief with great regularity[30–32 39 42] (median SQS=85%; range 80% to 95%, n=5 studies), yet they learnt to employ a number of strategies (most notably, engaging with their spirituality[31–33 42] (median SQS=93%; range 85% to 98%, n=4 studies)) to cope with this and with their roles as volunteers in general. Depner *et al* suggest that the exposure of inmate volunteers to death, dying and grief and their development of effective coping strategies could be acting as a catalyst for positive psychological changes in these prisoners.[32]

DISCUSSION

What recommendations can be made for the future provision of palliative and end of life care in prisons?

Relationships both inside and outside of prison are important to prisoners nearing the end of life. When prisoners have been incarcerated for a long time, 'family' may include or be limited to the individuals who have been serving a sentence alongside the prisoner. Yet taking practical steps to ensure access to loved ones involves balancing the care needs of the individual with the custodial and security demands of the organisation. For example, ensuring family have access to a dying prisoner on a prison wing is problematic if it involves the prolonged locking up of all other prisoners on the wing, or an excessive number of custodial staff to escort and ensure the safety of the prisoner's family. Likewise, if a prison does not have adequate facilities for palliative and end of life care delivery, then moving a prisoner to another custodial institution should be considered on a case-by-case basis in consultation with the prisoner. For some, this move may effectively sever ties with the only 'family' they have. However, insufficient clinical facilities are not the only barrier presented by the prison environment. The physical layout of a prison, by virtue of being a secure institution, is at odds with the delivery of palliative and end of life care equitable to that which is available in the community. Yet we have also acknowledged that prison may be the only appropriate setting for some prisoners at the end of life. This conflict begs the question: What can

individual clinicians and prison staff do to ensure a high standard of palliative care is delivered in their prison?

Prison nurses already employ a wide range of skills that are unique to the challenging environment in which they work. One aspect of this role should involve advocating for the early release on compassionate grounds of any prisoner with palliative care needs who is increasingly immobile, or is likely to die soon. In addition, they should consider whether or not continued incarceration is likely to shorten life expectancy. These are important factors which will be considered in any decision regarding early release on compassionate grounds in the UK.[47] Prisoners have poorer health than the general population, and therefore prison healthcare staff must be vigilant when monitoring for deterioration. Tools such as supportive and palliative care registers can help monitor for this deterioration, and healthcare staff should ensure that they take responsibility for the updating of these registers. For those prisoners who will die in prison, by choice or by a lack of any alternative, the care delivered must be of an appropriate standard. Inmate hospice volunteers are invaluable to palliative care delivery in prisons, and are well received by the prisoners they care for. However, when introducing a volunteer model, prison management and senior healthcare staff must account for the frequent exposure to grief that these volunteers will experience. In spite of the potential for posttraumatic growth and rehabilitation that comes with the role, the well-being and mental health of volunteers must be safeguarded.

As a team, it is beneficial for prison officers, healthcare staff, inmate volunteers and the prisoners involved in their care to reflect on the values and the humanity they share, in order to foster better team relationships and to ensure that all are focussed on achieving the same goals with regards to palliative and end of life care in prison. There are clear structures and hierarchies within a prison which are essential to its functioning, and this recommendation does not seek to challenge them. However, acknowledging the reality and universality of death was linked to better attitudes towards palliative care in prisons. Perhaps if not all staff are inclined to think about the issues in this way, then it should be the role of prison management and senior healthcare staff to ensure that health and custodial staff are placed in areas that are best suited to their individual skills.

What does this review add?

The previous systematic review by Wion and Loeb[1] provided the rationale for limiting the date range of the literature search in this rapid review to 2014 to 2018. In their review, Wion and Loeb discuss their findings in the context of the previous reviews by Stone *et al*[13] and Maschi *et al*.[16] Therefore, it is important to consider what this review adds to the preceding systematic review. Many of the key findings of this review reinforce points made in the Wion and Loeb review, such as the value of inmate hospice volunteers and the physical barriers presented by the prison environment. Other findings which were relatively minor in the previous review have become major themes in the literature published since 2014, such as the importance of maintaining family relationships, and the potential grief burden of inmate hospice volunteers. Finally, this review adds the main finding that relationships both inside and outside of prison are of importance to prisoners at the end of life, and recommends that those involved in their care should support prisoners to maintain these relationships.

Research implications

Wion and Loeb's systematic review in 2016[1] identified 19 primary research articles published between 2002 and mid-2014. This rapid review identified 23 primary research articles published between 2014 and 2018. Four articles featured in both reviews.[31 36 39 42] The significant increase in the average number of studies published per-year across the two reviews (5.75 per-year in this review and 1.5 per-year in Wion and Loeb)[1] demonstrates the growing commitment to understanding and improving palliative and end of life care in prisons. Previous reviews have also noted that that the majority of research into palliative and end of life care in prisons originates in the USA[1 13]; this review has identified that a small, but growing number of studies are being published in the UK,[4 35 38 45] France[2 46] and Switzerland.[3 34 37]

Both the proportion and the absolute number of people imprisoned in the USA (655 per 100 000; or 2 121 600 in 2016) is the highest in the world, significantly higher than England and Wales (139 per 100 000; or 82 543 in 2019) or Scotland (147 per 100 000; or 8020 in 2019).[48] In addition, the model of providing end of life care in the USA is structured around prison-based hospices often with inmate hospice volunteers providing a large amount of care. The approach in the UK is based on community hospices providing support to patients and staff in the prison.[13] Because of these differences, more research is needed into palliative and end of life care in prisons in countries outside the USA. There is also a need for more studies using quantitative and experimental methods, possibly to measure the efficacy of some of the interventions that are frequently identified as being of benefit to palliative and end of life care in prisons, such as the inmate volunteer model. Wion and Loeb[1] identified the need for the voices of prisoner's families and healthcare staff to be heard, and a small number of studies have emerged which have done this to an extent[2 35 45]; however, more studies are needed.

When considering the wealth of studies found which employ qualitative methods (74% in this review, 58% in Wion and Loeb),[1] it becomes apparent that any future synthesis of this research should employ methods which are best suited to this data. A thematic synthesis such as that outlined by Thomas and Harden[49] should be considered either as part of, or adjacent to a further systematic review.

Strengths and limitations of this study

The limitations of this study are the limitations which can be attributed to any rapid review. In order to achieve a

timely result as part of a larger project, this review streamlined the systematic review process by limiting the date range and number of databases searched, having one author perform screening with verification from a second, and conducting a narrative synthesis of results. As a result of this, there is the possibility that some grey literature and articles located outside the databases searched would not have been found. In addition, there were a number of primary research articles included in the previous systematic review which were not included due to the need to streamline the process.

However, when considering these limitations, it is important to consider that some studies have found congruity between the results of rapid and systematic reviews on the same subject.[18] In addition, this review synthesises the findings of 23 primary research articles from a 4 year period, compared with 19 articles from a 12.5 year period in the previous systematic review.[1] In doing so, this review has demonstrated the significant growth in the body of literature over a short period of time. This review also synthesised several new papers on inmate hospice volunteers for the first time, as well as studies from countries such as France and Switzerland. Many have only been published since the last systematic review.

- Relationships are of paramount importance to prisoners at the end of life. This includes relationships with friends both inside and outside of prison, and with family members. Efforts should be made to maintain these relationships.
- Inmate hospice volunteers can forge close bonds with the prisoners in their care, but can also experience a great deal of grief as a result of their job. They may be an effective way of delivering care to prisoners at the end of life, but their well-being should also take priority.
- The regime and physical environment of a prison conflicts with best practices in palliative and end of life care. This must be considered when planning service delivery for this population.

Twitter Bridget Margaret Johnston @BridgetJohnst

Acknowledgements The authors would like to thank Paul Cannon, college librarian at the college of Medical, Veterinary and Life Sciences at the University of Glasgow, for advising on and reviewing the search strategies.

Contributors BMJ conceived the idea and formulated the initial research questions. CMP wrote the protocol and developed initial search strategies. CMP undertook searches and screening of articles, BMJ verified the excluded articles. CMP and BMJ conducted quality appraisal independent of one another, and agreed final scores as described in the article. CMP conducted data extraction and data analysis with verification from BMJ. CMP wrote and revised the manuscript with notes from BMJ.

Funding This review constitutes part of a larger project titled the Evaluation of Macmillan End of Life Care in Prisons Service, funded by Macmillan Cancer Support Scotland (2018-2019).

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

ORCID iD

Chris McParland http://orcid.org/0000-0003-1575-3390

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