

Gender Disparities in End of Life Care: A Scoping Review

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Abstract

Objective: Traditional gender norms and expectations may disproportionately constrain in-home palliative care received by women. This scoping review aims to canvass and evaluate the literature on gender disparities in end of life care and explore relevant themes that could inform future research and practice. **Methods:** A systematic search of MEDLINE, OVID, COCHRANE, and EMBASE was conducted using MeSH terms palliative care, palliative medicine, terminal care, or hospice care, combined with gender equity, sex factors, sexism, or gender disparities. Articles were limited to those in English (2010 to 2021), focusing on end of life care, gender roles, patients, and caregivers. **Results:** Of 624 articles identified, 15 met inclusion criteria for critical appraisal using the AMSTAR checklist for systematic reviews and NICE guidelines for quantitative and qualitative studies. Most studies were of poor to moderate quality. Thematic analyses identified 6 major themes related to gender disparities: living situation, symptom experience, care context, care preferences, caregiving, and coping strategies. **Conclusion:** Larger scale research of better quality is needed to fully characterize gender disparities in end of life care and understand how physicians might mitigate these disparities by building awareness of personal gender biases, providing support to families, educating them, and initiating care discussions that overturn traditional and stereotypical gendered expectations.

Keywords

gender equity, gender roles, health & gender, sociology of sex and gender, palliative care, palliative medicine, palliative medicine & chronic care

Introduction

Early integration of palliative care and excellent symptom management have been shown to produce significant benefits for quality of life at the end of life.¹ As a result, there has been a push towards better community palliative care that enables patients to remain at home and avoid crisis admissions and interventions that are not within their goals of care. However, little research has examined whether these benefits hold true regardless of sex or gender.² By sex we mean the biology of being a man or woman whereas gender is used in a social sense, to describe the opportunities and constraints arising from sex roles. We differentiate gender from individually defined gender identity. A shift towards more care in the home may disproportionately burden women, who traditionally are society's informal care-providers. Supports women and men have available to them at the end of life may differ.^{3–5} Some of these differences arise from deeply rooted gender norms and roles that society has traditionally deemed acceptable despite their embedded inequities, creating disparities between women and men in terms of place of death, amount and type of support offered, likelihood of accepting palliative care, or experiences of symptoms such as fatigue, and caregiver burnout.^{3–9}

Although there is extensive documentation that sex/gender has a large influence on experiences, preferences, and care received at the end of life,^{4–17} and one review of women as care-givers,³ much of the research on palliative care has inadvertently

neglected to study the effect of gender, particularly on care receiving.⁵ This remains a largely unrecognized obstacle to providing palliative care that is universally beneficial. Healthcare providers are not able to cater care to the needs of each patient and family unit without applying a lens that reveals deeply rooted gendered constructs and expectations.^{4,5,8,18} This lack of insight fails men and women in different ways, as they struggle and grapple with the impact of very different ingrained beliefs. For example, men are often implicitly taught that they must be stoic, strong, and not express any emotion or ask for help, and instead, 'fight' for a cure until the very end.^{12,19–21} Traditional socialization of women, in contrast, is to be caring, sensitive, and willing to put others first despite any burden to themselves.^{4,22–24} These ingrained beliefs significantly colour what either group thinks is expected of them at the end of life and shape the types of supports, treatments, and communication they seek or need from healthcare providers.

Since ideal end of life care is holistic, patients cannot be separated from their family or caregivers. It is therefore not only the

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sex/gender of the patient that can affect disparity, but that of caregivers as well. Women, as the traditional carers in most societies, often have spent a lifetime providing informal care, without being recognized for such efforts.^{3-5,24} Their work is hence rendered largely invisible and often undervalued, which may unintentionally deplete their emotional reserve. This can affect the choices they make for themselves at the end of life. Having experienced the effort required to be a caregiver, they may feel guilty about, and choose not to burden family members with that same weight and responsibility.^{5,8,15,18}

Despite increasing recognition of gender as a determinant of health, research on the extent and complexity of gender disparities in end of life care is limited, and evaluations of the strength of existing evidence are lacking. This study aims to fill that gap by identifying and mapping out relevant concepts creating gendered disparities in end of life care, evaluating the quality of the evidence backing these concepts, and identifying gaps in existing research to inform future research direction. A scoping review was chosen as the research design due to the expected heterogeneity of the concepts being mapped and the lack of precision in the clinical research question being asked, making it the best design for exploring a wide array of themes while retaining a systematic methodology for combing through the literature.²⁵

Methods

Design: The methods were developed following the JBI scoping review method guideline and the PRISMA checklist for scoping reviews.^{25,26}

Data Sources: A systematic search of MEDLINE, OVID, COCHRANE, and EMBASE was conducted, with the help of an information sciences specialist at Queen's University.

Search Strategy: The following MeSH terms were used: "palliative care", "palliative medicine", "terminal care", or "hospice care", combined with "gender equity", "sex factors", "sexism" or "gender disparities". The term "end of life care" was originally searched as well but did not exist as a MeSH term within the databases searched. The MeSH term "terminal care" was returned instead, which was then used to find all other related MeSH terms in the database, including "palliative care", "palliative medicine", and "hospice care". "Male" and "female" specifically were excluded as search terms, as most articles use these terms to refer to biological and medical differences rather than differences in gender norms or roles.²⁷ In addition, all studies mentioning male or female as a baseline demographic variable or subgroup would have been returned in the search, unnecessarily inflating the number of irrelevant articles for review.

Eligibility Criteria: Articles were limited to those in English and those from 2010 to 2021, to examine more recent research on the topic with an arbitrary cut-off point of 10 years prior to the inception of the idea for this research project in 2020. All articles identified in the search were exported to an Excel document, where titles and abstracts were screened for eligibility by

the primary author. Articles without a focus on end of life care or gender roles were excluded, as were those that focused on sex differences among healthcare providers or researchers rather than patients and their families. No specific types of literature were excluded. Retained articles were then subjected to full text review by the primary author and those that did not focus on the relevant topics as mentioned above were also excluded.

Quality Assessment: The primary author independently used the AMSTAR checklist for appraising systematic reviews (Appendix 1)²⁸ and the NICE guidelines for appraising quantitative or qualitative studies (Appendices 2-3) for the remaining articles.²⁹ Other literature types were included in the scoping review, but critical appraisal was not possible for literature that did not conduct a study. Articles were classified as weak if there was no study presented that could be critically appraised, or they fulfilled less than half of the checklist items for either AMSTAR or NICE guidelines. Articles were classified as moderate if they fulfilled at least 50% of checklist items, and strong if they fulfilled all checklist items with only minor points of potential improvement identified.

Data Extraction and Synthesis: A table was created to chart the article title, year of publication, location of the study, care context (inpatient, community, hospice), strength of each article, reasons for the strength rating, and descriptive analyses of findings from each article (Table 1). Data was extracted by the primary author, by combing through included articles and listing findings discussed that were relevant to the effects of gender roles on end of life care. These findings were summarized into the table as descriptive analyses, which were then coded into hierarchical themes in a thematic analysis through colour coding, looking at all domains in which gendered differences were demonstrated. The second author then reviewed and verified the data extraction, critical appraisal, descriptive analyses, and the organization of concepts into themes through the thematic analysis. The manuscript was then written by both authors, following PRISMA guideline for scoping reviews (Appendix 4).²⁶

Results

A systematic search of the databases in August 2021, returned a total of 624 articles, of which 335 were duplicates and 274 were excluded, leaving 15 articles that met inclusion criteria for the scoping review (See Figure 1 for details regarding exclusions).

Critical Appraisal of Studies

The 15 articles that were critically appraised included one systematic review, six quantitative studies, six qualitative studies, one letter to the editor, and one critical essay. These studies were published between 2011 and 2020, and were conducted in Canada, USA, England, Sweden, Germany, Portugal, and New Zealand. The AMSTAR checklist and NICE guidelines were used to appraise papers based on study format.^{28,29} The letter to the editor and the critical essay were read for additional

Table I. Table summarizing critical appraisal and descriptive analyses from each of the 15 studies included in review. Table includes article title and year of publication, strength rating, checklist used, context of study (where relevant), reasons for rating, and key findings and themes.

Article Title (Year)	Strength Rating	Reasons for Rating	Findings & Themes
Differences in Symptom Distress Based on Gender and Palliative Care Designation Among Hospitalized Patients (2016) ³⁰	Moderate (NICE quant). Inpatients in Sweden.	Pro: Exploratory secondary analysis with reasonable effect sizes & p values/CI. Con: No details of subgroup analysis, no power calculation, not generalizable outside admitted pts & excluded dementia.	Females: More live alone. More pain, fatigue, nausea despite similar documentation by HCPs.
Differences in Terminal Hospitalization Care Between U.S. Men and Women (2016) ³¹	Moderate (NICE quant). Inpatients in US.	Pro: Large sample size. Adjusted for many variables. Precise, narrow CIs. Cons: No validation or justification for outcome measures picked. Small effect size. No detail on subgroup analysis. Info by billing/claims alone (unclear if SDM vs patient vs default decision of code status). Only 20% of all discharges included. Only inpatients in US hospitals.	Females: Older, less likely to be married. More likely under general care versus specialist care, shorter hospitalizations. More likely to have DNR & less likely receive ICU care.
Gender and family caregiving at the end-of-life in the context of old age: A systematic review (2016) ³	Weak (AMSTAR).	Pro: Relevant. Thorough & explicit search. Multiple reviewers. Cons: No description of included/excluded articles. Did not include assessment of articles. No risk of biases or heterogeneity discussed. No evaluation of internal/external validity of any included studies. No details on "feminist quality appraisal framework" mentioned in study.	Female: Caregivers more mental & physical strain (societal expectation to provide more care at end of life, home care increase responsibility of women). Less likely to receive informal care, not wanting to be burdened. More likely live in poverty.
Until the very end: is there equity in palliative care? (2014) ³²	Weak (letter format).	Letter to editor. Difficult to appraise as no study conducted.	Perspective on cultural norms affecting gender influences on end of life. Females: Live longer, lower salaries. Husband dies at home with care from wife & uses old age pension. Less \$ and need to go to nursing home for wife. Husbands not allowing palliative care or means to access. Social castigation.
Gender differences in prevalence of depression among patients receiving palliative care: the role of dependency (2011) ³³	Weak (NICE quant). 1 hospice London.	Pros: Thorough dependent variables included. Confounders adjusted. Strong effect size. Cons: Wide CI. No power calculation, sample size 300 arbitrarily chosen. Depression measured via yes/no validated scale instead of spectrum or severity. No rationale for changing categorical variables to binary. Only 1 hospice in London, study funded by this hospice. 40% participation.	Males: Equal or more depression than F compared to outside palliative context. Dose response effect between level of dependency & depression in men.
Gender Differences in Caregiving at End of Life: implications for Hospice Teams (2015) ⁷	Weak (NICE quant). 2 hospices NW USA.	Pros: Adjusted outcomes for demographics. Internally consistent scale for burden across 5 domains.	Females: Caregivers lower self esteem, more negative impact on schedule, health and family support.

(continued)

Table 1. Continued.

Article Title (Year)	Strength Rating	Reasons for Rating	Findings & Themes
Preference for Palliative Care in Cancer Patients: are Men and Women Alike? (2018) ¹⁴	Weak (NICE quant). 2 cancer centres Buffalo NY and Sacramento CA.	<p>Cons: Secondary analysis off RCT. No info on selection & potential biases. Demographic table had no p values/significance. Small effect sizes, no power calculation. CIs close to 1. Internal validity outcome measure only 0.62-0.83. No info on who did analysis or potential biases. Only applicable to 2 hospices in NW USA, caregiving burden likely greater in home versus hospice.</p> <p>Pros: Logistic & ordinal regression adjusting for confounders. Good effect size.</p> <p>Cons: CI wide, no power calculation. Secondary analysis off cluster RCT but no info about selection (even original VOICE trial no discussion of selection bias or % participation). No calculation of power for clusters. No discussion of how many researchers or inter-rater reliability. No rationale for why excluded hematologic cancers. Outcome measure not validated. Subjective 5 item scale arbitrarily turned into binary variable. Only represents clinic/ community sample in 2 US cities.</p>	<p>Females: More likely prefer palliative care, no difference based on education level (could be under powered). Societal beliefs push men to “fight” disease. Focus on helping men understand benefit to family.</p>
Exploring the gender dimension of problems and needs of patients receiving specialist palliative care in a German palliative care unit-the perspectives of patients and healthcare professionals (2019) ⁶	Moderate (NICE qual). 1 inpatient palliative unit Germany.	<p>Pros: Relevant. Defensible design. Aim clear. Purposive stratified sampling for diversity.</p> <p>Cons: No discussion of how they minimized selection bias or cherry-picking patients. Limited description of data collection, what was included in interview, or how they came up with word cards. No description of research explanation to participants. No reflexivity. Only 1 method of data collection. Small sample size. Social desirability bias. Bias depending on participants’ ability to reflect & introspect.</p>	<p>Females: More expressive coping strategies, care more about physical appearance, stronger need for communication & support, activate extended network. Worried about domestic & caring duties, worried more about being a burden.</p> <p>Males: Rely on partners more, greater expectation for care at home & autonomy, more reluctant to take advice from female HCP. Worried about transferring financial/legal duties. Expected partner to take caregiving role.</p>
Sex Differences in Quality of Life and Clinical Outcomes in Patients With Advanced Heart Failure: Insights From the PAL-HF Trial (2020) ³⁴	Weak (NICE quant). 1 centre Durham, NC, USA.	<p>Pros: Randomized. Reliable & validated outcome measures. Reasonable FU & loss to FU. Exploratory analysis off RCT.</p> <p>Cons: Underpowered subgroup analysis. No power calculation. Only 1 centre. No justification for only including high risk sample. Selection unclear. No % who agreed to participate. No mention of when ESCAPE score calculated. Excluded</p>	<p>Females: Greater symptom burden & poorer QOL, more had co-morbid depression. More widowed. No change in QOL with palliative care compared to change in QOL in men with treatment.</p>

(continued)

Table I. Continued.

Article Title (Year)	Strength Rating	Reasons for Rating	Findings & Themes
Witnessing a body in decline: Men's and women's perceptions of an altered physical appearance (2016) ³⁵	Weak (NICE qual). 2 hospices near Lisbon Portugal.	<p>those with non cardiac terminal illness (not generalizable). Did not define "terminal illness". No blinding though likely could have blinded cardiology team. Authors are cardiologists – conflict of interest. Unclear how much crossover. No mention of # lost to FU in each group. Significant baseline differences (HFpEF more in F). No effect sizes. Graph lines not labelled (range, IQR, CI?). Precision unable to assess but lines overlapping and study underpowered.</p> <p>Pros: Relevant. Clear aim. Organized result presentation.</p> <p>Cons: No detail on methods or how interview conducted/ structure. No discussion of biases, how participants selected, % agreeing to participate. No reflexivity, one researcher. No ethical discussion/approval. No discussion of how conclusions drawn from data. Small sample size without justification. No inclusion/ exclusion criteria. Not generalizable outside Portugal (culture differences).</p>	<p>Females: Appearance is more of social currency & value. More discrimination against F with obvious aged appearance (objectification of women). Similar importance of weight in F versus M. Hair loss more effect on F because linked to femininity – hair dye & painting nails = control/ agency.</p>
Gender and the language of pain in chronic and terminal illness: A corpus-based discourse analysis of patients' narratives (2018) ³⁶	Strong (NICE qual). Database by University of Oxford.	<p>Pros: Relevant, clear aim. Results presented organized. Good research design with qualitative & quantitative approach. Dataset vigorously & systematically collected. Analysis thorough, systematic & well explained. Conclusions in depth. Good discussion of limitations & practical implications for practice. Mostly generalizable.</p> <p>Cons: Limited to 16 common conditions, may not be generalizable to everyone if they don't have one of these.</p>	<p>Females: Refer to pain more, wider lexical repertoire to describe, use more cognitive & psychological words. Routinely undertreated for pain (seen as exaggeration, anxiety or emotional distress). Pain more "natural" for females. More sadness & crying. More likely to share pain with HCP & treat as shared goal, more likely to use pluralistic/holistic healthcare methods.</p> <p>Males: Taught to suppress expression of pain because "unmanly". Use more facts & descriptions. More anger. Discussion surrounds helplessness & vulnerability. Reliance on wife more.</p>
Gendered Processes in Hospice Palliative Home Care for Seniors With Cancer and Their Family Caregivers (2016) ²⁴	Strong (NICE qual). Hospice program at Western University.	<p>Pros: Relevant, clear aim. Well thought out research design with validated methods. Ethnographic methods of triangulation used. Multiple data informants, methods, theories/perspectives. Researcher role clearly defined with excellent</p>	<p>Regulating gender relation: Assert power: HCP delegate more work to female caregivers. Male caregivers assume nurses do all caring, appeals to physician to help make decisions instead (man's job).</p> <p>Normalizing gender relation:</p>

(continued)

Table I. Continued.

Article Title (Year)	Strength Rating	Reasons for Rating	Findings & Themes
		reflexivity. Analysis systematic and themes related by diagramming. Reviewed by co-authors. Cons: Population not that diverse (all White sample, all nurses were F). Could have used multiple researchers for more perspective.	Females expected to do physical care work, males more buying supplies/meds etc Blurring of “caring for” with “caring about” for F. Equalizing gender relation: Deflect gender as a contributing factor. HCPs claim to treat M/F same. Though F caregivers assume most care they are not thought to (renders work invisible).
Critically examining diversity in end-of-life family caregiving: implications for equitable caregiver support and Canada’s Compassionate Care Benefit (2012) ³⁷	Moderate (NICE qual). PCP from BC, MB, ON, QC, NL from admin, clinical, home care settings.	Pros: Relevant, clear aim. Diversity of provider roles & settings. Data analysis rigorous, reviewed by multiple investigators. Cons: Evaluating CCB use with “utilization focused evaluative approach” but did not study in intended users (caregivers) so does not fit with outlined approach. Sample limited to 5 provinces. Unclear what patient diversity is & no context for patients. No method triangulation. One researcher conducted interviews, no reflexivity.	Many not aware of CCB, access affected by intersectionality. Females: Less likely to qualify because stay home or part time work. Get less with it due to lower income. Males: Less likely to receive benefit, underutilization for their often female patient. Need to be taught caring roles & managing home.
‘Because it’s the wife who has to look after the man’: A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life (2017) ⁴	Moderate (NICE qual). Focus groups in New Zealand.	Pros: Relevant, clear aim. Two researchers conducted focus groups. Findings convincing and results reported in organized manner under 3 main themes. Vignettes were previously deemed useful in research. Cons: Study population lacks diversity (white, heterosexual, older women) even though men present in group. Selection bias through recruiting in community organizations that lobby for older people. Only one method data collection. Vignettes to stimulate discussion very gender normative. No role descriptions or reflexivity. Insufficient detail on thematic analysis.	3 themes: Expectation that women care (despite burden), women’s duty to care (internalized gender normative beliefs), women’s construction of men. Females: Community care really means unpaid care by families which usually burdens women more. Depression & caregiving strain higher. Norms of expectation to care compassionately & sympathetically, being sensitive to others, willing to put others before self even if ill health. Duty as “good daughter or wife”. Often assumed as carer & supports provided instead of assumption challenged. Males: Need to be seen as strong, independent, self-sufficient.
Gender and palliative care: a call to arms (2020) ⁵	Weak type of study as only critical essay but strongly presented.	Critical essay , literature review. Difficult to critically appraise as no study done. Pros: thorough discussion, offers insight into complexity of issue (also have to consider intersectionality, gender as no longer a binary construct). Good	Females: Experiences less visible. “Unfeminine” if put career before being wife/mother. Less likely to seek & accept formal support, usually invisible & economically undervalued work. Expectation to provide care so husband can have good death. Guilt/feeling of failure when cannot. HCP assume F need

(continued)

Table 1. Continued.

Article Title (Year)	Strength Rating	Reasons for Rating	Findings & Themes
		practical steps at end for research & for practice.	less help caring. More fatigue & greater severity. Continue to do housework & care post diagnoses. More accepting of palliative care but do not benefit from early integration as much as men. Accept dying outside home due to fear of being burden after living longer & being caregiver. More likely poverty (unequal pay/working conditions). Males: Less likely report emotional concerns. More likely to die at home.

Thematic Analysis Legend: Living situation Care context Symptom experience Care preferences Caregiving Coping strategies.

perspective and used to confirm consistency, but since neither reported a study, critical review options were limited. Overall, most studies were of poor to moderate quality. Eight were classified as weak, five as moderate, and two as strong, using the rating described in the methods section (Table 1).

Thematic Analysis

Descriptive analyses were carried out for each of the studies included in the review and their findings were included in the critical appraisal table (Table 1). Thematic analysis was then conducted to synthesize heterogeneous data into themes that could be presented in an organized fashion. Findings from each study were coded by the primary author into 6 general themes: living situation, symptom experience, care context, care preferences, caregiving, and coping strategies.

1. **Living Situation:** Studies appraised showed women were less likely married, more likely to be widowed and more likely to be living alone at the end of life.^{30,31,34} This is in keeping with demographic trends, in that women outlive men and tend to be older at the end of life.^{31,32} However, this longevity did not translate into well-being, as many chronic diseases and chronic pain conditions were more prevalent among women.⁵ Oftentimes women were left alone at the end of life after having expended much time, energy, and resources to care for spouses and help them have a good death, leaving these women without a spouse and with fewer resources as they approached death.^{5,32} Compounding this, was the reality that women were more often found to be living in poverty relative to their male counterparts, owing to a lifetime of unequal pay and working conditions resulting from gender inequities earlier in life.^{3,5,32}
2. **Symptom Experience:** Women consistently reported more pain, fatigue, and nausea, despite this difference not being evident in medical charts or documentation.³⁰ It appeared

that although women reported more symptoms, they were not heard by their healthcare providers and were consistently under-treated for pain, reflecting a societal belief that among women, pain is likely exaggerated, related to anxiety and emotional distress, and is a “natural” process that needn’t be treated.³⁶ In addition to greater symptom burden, women did not experience the same improvement in quality of life as men when palliative care was initiated.^{2,5,34} Perhaps the finding that women tended to worry about their unmet responsibilities for domestic and caring duties is related, whereas men’s concerns centered on financial and legal duties, in keeping with gendered role expectations throughout life.⁶ Men described more depression at the end of life, a reversal of the trend seen in the general population and perhaps related to the expectation that men should be independent. One study found a dose dependent relationship between the frequency of depression and level of dependency.³³

3. **Care Context:** Women received medical care primarily from generalists such as family physicians, whereas men were more likely to have specialists involved.³¹ This may have been linked to men’s expectations about ‘faint hopes’ of a cure, while women accepted death and looked to the continuity of long term relationships with generalists as a source of support.^{12,14,19–21} Women also had shorter hospitalizations, and were more likely to die in nursing homes rather than at home.^{5,31,32} This finding appeared to be related to women’s greater willingness to accept formal care so as not to be a burden on family members,^{3,5,6,8,15,18} coupled with more limited possibilities for informal care after outliving their spouses.^{31,32}
4. **Care Preferences:** More women tended to have a ‘do not resuscitate’ (DNR) order in place and, compared with men, fewer received care in an ICU.³¹ Women were less likely to ask for or prefer informal care from family members, fearing being a burden to others, and were more accepting of dying

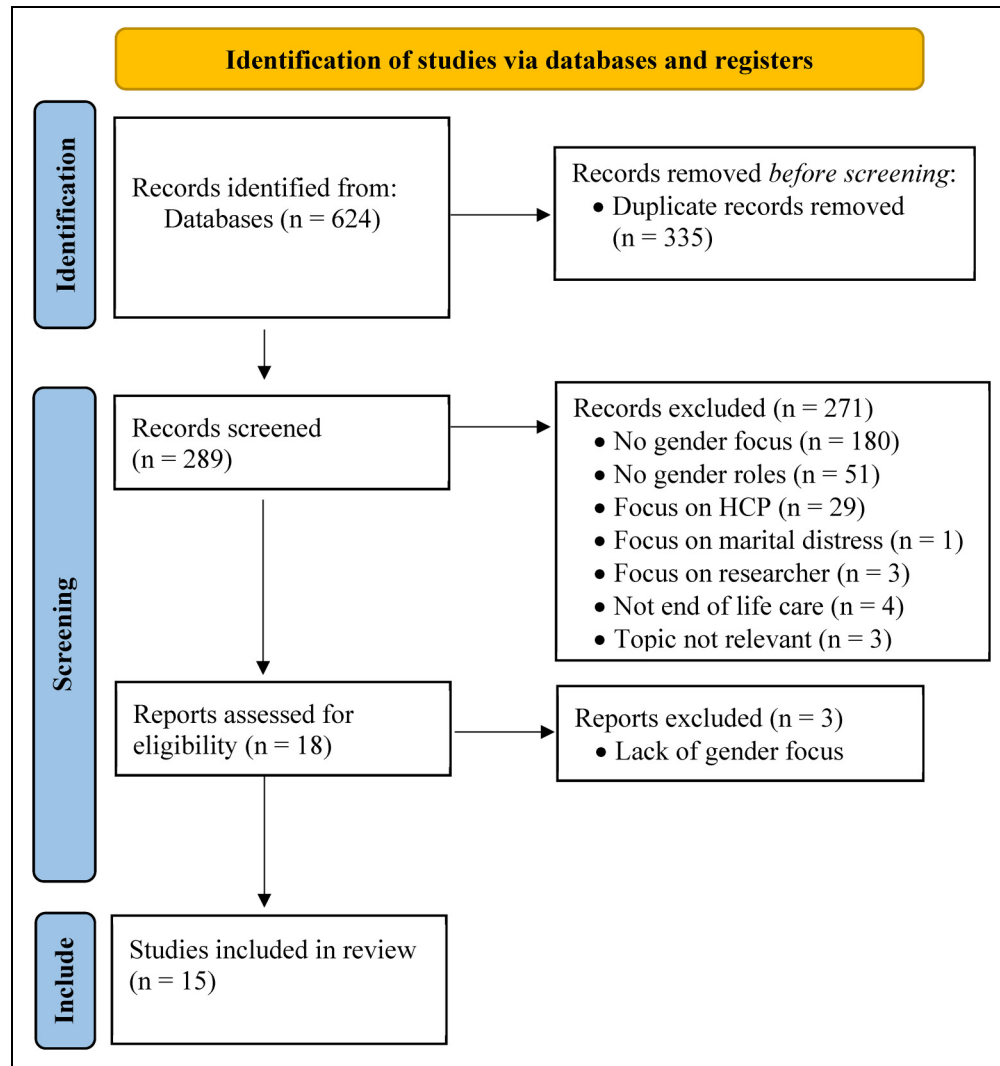


Figure 1. PRISMA 2020 flow diagram for identification of studies, which included searches of databases and registers only.

outside the home to alleviate this burden.³ Women disproportionately preferred palliative care rather than heroic attempts at cure, but were also less likely to benefit from early palliative care relative to men.^{2,5,34} Men on the other hand, had higher expectations of receiving care at home from their wives, and of retaining autonomy in making such decisions. They demonstrated gender bias in being more reluctant to take advice from female healthcare providers.⁶ One letter to the editor of a palliative care journal provided the additional perspective that there are cultures in Gambia or Kerala where husbands make decisions for wives and restrict their partners' access to palliative care. In some settings and with diagnoses such as HIV, women experience social castigation and can be ostracized from family, leaving them with no social network to provide end of life care.³²

5. **Caregiving:** Female caregivers experienced more mental and physical strain, had lower self-esteem and suffered greater fatigue.^{3,7} These deficits arose from greater expectations and responsibilities placed on women as caregivers and

led to increased burdens on their own health, all linked to the deeply ingrained and almost universal belief that women are the natural carers of society.^{3-5,24} Female caregivers consistently felt it was their "duty" to take on this role even after being diagnosed with multiple medical conditions, leading to heightened feelings of guilt or failure when they were unable to do so.^{4,5}

Healthcare providers' approaches were not exempt from gender bias. At times, they delegated physical care tasks to female, and decision making to male caregivers.²⁴ They also provided more support to male caregivers, who were seen as "heroic" in providing care outside their gender role, while women were not offered the same support.^{5,24} Women were assumed to inherently be more compassionate, sensitive to others, and willing to put others before themselves regardless of the woman's health. They were expected to care about and for a loved one, whereas men were not held to the same standard.^{4,24} Healthcare providers were unaware of their unequal expectations of males and females and essentially rendered women's work invisible

and undervalued.^{5,24} In terms of formal supports, female caregivers were less likely to qualify for various government financial support benefits offered to caregivers, as these were generally linked to employment and women were more often unemployed or involved in part-time work. When they did qualify, they often received less money, again related to women's lower incomes across occupation and location. Men, however, applied for and, therefore, received such benefits less frequently, suggesting that they underutilized this formal support, perhaps because they were less likely to provide care to their partners.³⁷

6. **Coping Strategies:** Women were more able to express needs and ask for help, while men tried to be strong and independent rather than voice symptoms or feelings.^{4-6,36} Women were also better at communicating about pain, using a wider vocabulary and including cognitive and psychological terms that were absent from men's descriptions.^{5,36} Symptom control was viewed as more of a shared goal by women who accepted pluralistic healthcare coping methods.³⁶ They often activated extended networks for support whereas men were more likely to only rely on their partners.^{6,36} Lastly, women valued and used physical appearance more at end of life to retain control and agency, particularly women from cultures or locations that place a stronger value on appearance.^{6,35}

Discussion

Overall, gender bias appeared to permeate many aspects of end of life care. Although research on such sex/gender disparities has been conducted in the past ten years, most studies had small sample sizes and lacked enough detail on selection, methods, and data collection to achieve internal validity. External validity was also limited, as most involved only one or two centres with patients from specific cultural contexts or locations (eg, inpatient or hospice populations), or with specific medical conditions. Despite these gaps, the literature identifies significant sex/gender disparities for care giving and receiving and in multiple domains of end of life care. The push for more end of life care in the community may unfairly burden women who shoulder most caring duties but receive less care support.^{3-7,24,34} Six domains or themes were specifically identified, under which gender disparities fell: living situation, symptom experience, care context, care preferences, caregiving, and coping strategies. All of these were clearly linked to deeply ingrained social constructs of sex/gender with each creating inequitable expectations at end of life.

By the end of their lives lifelong inequities in pay and working conditions leave women with limited financial resources compared to men.^{3,5} Women's greater life expectancy brings with it the harm of widowhood and of living alone when death approaches.^{31,32,34} Unfortunately, a longer lifespan also brings greater burden of symptoms and suffering, perhaps somewhat linked to being society's natural 'caregivers' throughout life.^{4,7,30} By outliving their spouses, women are

disadvantaged at the end of life when there are fewer caregivers and resources left to provide for them.³² They are more likely to accept formal care and dying in an institution rather than at home to avoid being a burden, one they may know well having often provided home care to their spouses.^{3,6} That caregiving work can be rendered invisible by healthcare providers, who subconsciously put in place more support for male caregivers since they are seen as 'unnatural' in this role.²⁴ Perhaps this lifelong toll of continuing to dutifully care even after receiving multiple medical diagnoses or nearing the end of life is offsetting some of the benefit women should receive with earlier palliative care, and resulting in a disparity in benefit.^{5,34} Women, but not men, emphasize appearance as an important coping mechanism. This is likely related to the social currency of a woman's appearance, which has been linked to value and identity in a way that does not hold true for men. Appearing old and losing hair is much more stigmatized for women and acceptable for men, so women are more likely to dye their hair, paint their nails or wear wigs, attempting to retain status and value in society.³⁵

Ignoring the effect of gender constructs also disadvantages men who are taught that they must be strong and tough, that expressing emotion is "unmanly", and that vulnerability is a weakness.^{4,21} This can discourage seeking end of life support or communicating feelings and symptoms to healthcare providers. Men then rely more on themselves rather than an extended network for support, and after a lifetime of suppressing feelings, have more difficulty communicating needs, fears, or perceived weaknesses.^{6,14,36} Men could, instead, be encouraged to express their emotions and symptoms and approach others for support, rather than succumbing to social pressure to remain silent and strong. Boys need to be encouraged to talk about physical and psychological pain earlier in life so it becomes more natural and they develop a wider vocabulary for describing how they feel later on.³⁶ Experiencing vulnerability often equates to a loss of manhood, a core tenet of male identity; thus, acknowledging and/or revealing increasing dependence often precipitates struggles with depression.³³ Finally, men who do wish to assume the role of caregiver may be pushed aside as the unnatural choice, with a female caregiver being favoured.⁵

Implications for Research and Practice

We are cautious in making recommendations about palliative care practice given that this was a scoping review and papers identified did not demonstrate exceptional methodologic quality. Some conclusions do, however, seem reasonable and provide guidance for future research. Gender disparities in end of life care giving and receiving disadvantage both men and women, but in different ways. Subsequent research might consider whether and how social constructs of gender affect the type of communication, care, and support that patients and families need. Reflexivity is required to challenge gender assumptions, bring gendered processes to the forefront instead of allowing them to be rendered invisible in everyday practice, and to increase awareness of how physicians' own

socioeconomic status creates power imbalances that can influence interactions with patients and their families. The impact of discussing gender roles, relations, and biases in professional health care education is an area for potential research. The focus of such education and research on it might go beyond sex differences, to examine gender as a social process that interacts with and affects sociopolitical structures and other life circumstances.³⁶ How might patients and families become partners in challenging gender biased expectations? Finally, research that reveals whether systemic and gendered assumptions about caring determine both men's and women's roles in providing informal palliative care might be a first step in breaking down these stereotypes.²⁴

Limitations

Some might consider our focus on disparities between men and women to be a binary view that ignores the more fluid construct of gender identity, and therefore a limitation in scope. Our aim was to examine whether and how the expectations and constraints tied to sex/gender, affect end of life care. Gender identity, while not the same as the social construct of gender, likely does play a role in end of life care, but one that has already been studied and reviewed. This became evident when we undertook a secondary Medline search of 'palliative care' and 'gender identity' which yielded 13 papers. A title review limited this to two papers, 'Gendered Processes in Hospice Palliative Home Care for Seniors With Cancer and Their Family Caregivers',²⁴ and 'Expanding the Palliative Care Domains to Meet the Needs of a Community-Based Supportive Care Model (qualitative research)',³⁸ one of which was already included in our study, and neither of which addressed gender identity. However, when we searched 'palliative care and transgender (subject or keyword)' eight relevant papers were found, five of which were reviews done over a three year time-span.³⁹⁻⁴³ This seemed adequate and also surprising given the dearth of reviews about sex/gender bias in palliative care.

Another limitation is the omission of intersectionality in the scoping review. By this we mean that sex, alone, is only one of many social circumstances that might influence end of life expectations and care, and that its influence is not independent of other factors such as race, socioeconomic status, or geographic region.^{44,45} It would be important to study the intersecting impact of these factors on end of life care and the interconnected disparities that might result. This scoping review has only scratched the surface in examining intersectionality. Two articles demonstrated differential effects of gender in different cultures: the value attached to women's appearance in Portuguese culture³⁵ and cultural perspectives from Gambia and Kerala where there is an increased prevalence of HIV affecting gender dynamics.³² Finally, the review of the literature was primarily conducted by one author, whose social location - physician, Chinese cultural background, and female sex - also subconsciously provide a lens through which the research was analyzed and presented. This bias was minimized as much as possible by using objective checklists for appraising the

evidence and having the second author review and verify the findings.

Conclusion

Overall, more comprehensive and generalizable research of greater validity is needed to paint a better picture of sex/gender effects in end of life care. Nonetheless, research is still consistent in demonstrating that significant gender disparities exist in end of life care. Palliative care professionals can play a pivotal role in working to upend these disparities by building awareness of personal biases and using that awareness to provide support to patients and families, educate future medical professionals and patients/families, and initiate important care discussions that can overturn unequal gendered expectations.


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Appendices

Appendix 1. AMSTAR checklist for critical appraisal of systematic reviews.²⁸ Boxes are checked for the one systematic review that was included in this scoping review.

1. Did the research questions and inclusion criteria for the review include the components of PICO?

For Yes:

- Population
- Intervention
- Comparator group
- Outcome

Optional (recommended)

- Timeframe for follow up

- Yes
- No

2. Did the report of the review contain an explicit statement that the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol?

For Partial Yes:

The authors state that they had a written protocol or guide that included ALL the following:

- review question(s)

For Yes:

As for partial yes, plus the protocol should be registered and should also have specified:

- a meta-analysis/synthesis plan, if appropriate, and

- Yes
- Partial Yes
- No

- a search strategy
- inclusion/exclusion criteria
- a risk of bias assessment

- a plan for investigating causes of heterogeneity
- a plan for investigating causes of heterogeneity

3. Did the review authors explain their selection of the study designs for inclusion in the review?

For Yes, the review should satisfy ONE of the following:

- Explanation for including only RCTs
- OR Explanation for including only NRSI
- OR Explanation for including both RCTs and NRSI

- Yes
- No

4. Did the review authors use a comprehensive literature search strategy?

For Partial Yes (all the following):

- searched at least 2 databases (relevant to research question)
- provided key word and/or search strategy
- justified publication restrictions (eg language)

For Yes, should also have (all the following):

- searched the reference lists / bibliographies of included studies
- searched trial/study registries
- included/consulted content experts in the field
- where relevant, searched for grey literature
- conducted search within 24 months of completion of the review

- Yes
- Partial Yes
- No

5. Did the review authors perform study selection in duplicate?

For Yes, either ONE of the following:

- at least two reviewers independently agreed on selection of eligible studies and achieved consensus on which studies to include
- OR two reviewers selected a sample of eligible studies and achieved good agreement (at least 80%), with the remainder selected by one reviewer.

- Yes
- No

6. Did the review authors perform data extraction in duplicate?

For Yes, either ONE of the following:

- at least two reviewers achieved consensus on which data to extract from included studies
- OR two reviewers extracted data from a sample of eligible studies and achieved good agreement (at least 80%), with the remainder extracted by one reviewer.

- Yes
- No

7. Did the review authors provide a list of excluded studies and justify the exclusions?

For Partial Yes:

- provided a list of all potentially relevant studies that were read in full-text form but excluded from the review

For Yes, must also have:

- Justified the exclusion from the review of each potentially relevant study

- Yes
- Partial Yes
- No

8. Did the review authors describe the included studies in adequate detail?

For Partial Yes (ALL the following):

- described populations
- described interventions
- described comparators
- described outcomes
- described research designs

For Yes, should also have ALL the following:

- described population in detail
- described intervention in detail (including doses where relevant)
- described comparator in detail (including doses where relevant)
- described study's setting
- timeframe for follow-up

- Yes
- Partial Yes
- No

(continued)

Appendix I. Continued.

9. Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review?**RCTs**

For Partial Yes, must have assessed RoB from

- unconcealed allocation, and
 lack of blinding of patients and assessors when assessing outcomes (unnecessary for objective outcomes such as all-cause mortality)

For Yes, must also have assessed RoB from:

- allocation sequence that was not truly random, and
 selection of the reported result from among multiple measurements or analyses of a specified outcome

- Yes
 Partial Yes
 No
 Includes only NRSI

NRSI

For Partial Yes, must have assessed RoB:

- from confounding, and
 from selection bias

For Yes, must also have assessed RoB:

- methods used to ascertain exposures and outcomes, and
 selection of the reported result from among multiple measurements or analyses of a specified outcome

- Yes
 Partial Yes
 No
 Includes only RCTs

10. Did the review authors report on the sources of funding for the studies included in the review?

For Yes

- Must have reported on the sources of funding for individual studies included in the review. Note: Reporting that the reviewers looked for this information but it was not reported by study authors also qualifies

- Yes
 No

11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?**RCTs**

For Yes:

- The authors justified combining the data in a meta-analysis
 AND they used an appropriate weighted technique to combine study results and adjusted for heterogeneity if present.
 AND investigated the causes of any heterogeneity

- Yes
 No
 No meta-analysis conducted

For NRSI

For Yes:

- The authors justified combining the data in a meta-analysis
 AND they used an appropriate weighted technique to combine study results, adjusting for heterogeneity if present
 AND they statistically combined effect estimates from NRSI that were adjusted for confounding, rather than combining raw data, or justified combining raw data when adjusted effect estimates were not available
 AND they reported separate summary estimates for RCTs and NRSI separately when both were included in the review

- Yes
 No
 No meta-analysis conducted

12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?

For Yes:

- included only low risk of bias RCTs
 OR, if the pooled estimate was based on RCTs and/or NRSI at variable RoB, the authors performed analyses to investigate possible impact of RoB on summary estimates of effect.

- Yes
 No
 No meta-analysis conducted

13. Did the review authors account for RoB in individual studies when interpreting/ discussing the results of the review?

For Yes:

- included only low risk of bias RCTs
 OR, if RCTs with moderate or high RoB, or NRSI were included the review provided a discussion of the likely impact of RoB on the results

- Yes
 No

14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?

For Yes:

- There was no significant heterogeneity in the results
 OR if heterogeneity was present the authors performed an investigation of sources of any heterogeneity in the results and discussed the impact of this on the results of the review

- Yes
 No

15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?

For Yes:

- performed graphical or statistical tests for publication bias and discussed the likelihood and magnitude of impact of publication bias

- Yes
 No
 No meta-analysis conducted

16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?

For Yes:

- The authors reported no competing interests OR
 The authors described their funding sources and how they managed potential conflicts of interest

- Yes No

Appendix 2. NICE guidelines for critical appraisal of quantitative studies.²⁹

1.1 Is the source population or source area well described?

Was the country (eg developed or non-developed, type of healthcare system), setting (primary schools, community centres etc), location (urban, rural), population demographics etc adequately described?

1.2 Is the eligible population or area representative of the source population or area?

Was the recruitment of individuals, clusters or areas well defined (eg advertisement, birth register)?

Was the eligible population representative of the source? Were important groups under-represented?

1.3 Do the selected participants or areas represent the eligible population or area?

Was the method of selection of participants from the eligible population well described?

What % of selected individuals or clusters agreed to participate? Were there any sources of bias?

Were the inclusion or exclusion criteria explicit and appropriate?

2.1 Allocation to intervention (or comparison). How was selection bias minimised?

Was allocation to exposure and comparison randomised? Was it truly random ++ or pseudo-randomised + (eg consecutive admissions)?

If not randomised, was significant confounding likely (–) or not (+)?

If a cross-over, was order of intervention randomised?

2.2 Were interventions (and comparisons) well described and appropriate?

Were interventions and comparisons described in sufficient detail (ie enough for study to be replicated)?

Were comparisons appropriate (eg usual practice rather than no intervention)?

2.3 Was the allocation concealed?

Could the person(s) determining allocation of participants or clusters to intervention or comparison groups have influenced the allocation?

Adequate allocation concealment (+ +) would include centralised allocation or computerised allocation systems.

2.4 Were participants or investigators blind to exposure and comparison?

Were participants and investigators – those delivering or assessing the intervention kept blind to intervention allocation? (Triple or double blinding score + +)

If lack of blinding is likely to cause important bias, score – .

2.5 Was the exposure to the intervention and comparison adequate?

Is reduced exposure to intervention or control related to the intervention (eg adverse effects leading to reduced compliance) or fidelity of implementation (eg reduced adherence to protocol)?

Was lack of exposure sufficient to cause important bias?

2.6 Was contamination acceptably low?

Did any in the comparison group receive the intervention or vice versa?

If so, was it sufficient to cause important bias?

If a cross-over trial, was there a sufficient wash-out period between interventions?

2.7 Were other interventions similar in both groups?

Did either group receive additional interventions or have services provided in a different manner?

Were the groups treated equally by researchers or other professionals?

Was this sufficient to cause important bias?

2.8 Were all participants accounted for at study conclusion?

Were those lost-to-follow-up (ie dropped or lost pre-, during or post-intervention) acceptably low (ie typically <20%)?

Did the proportion dropped differ by group? For example, were drop-outs related to the adverse effects of the intervention?

2.9 Did the setting reflect usual UK practice?

Did the setting in which the intervention or comparison was delivered differ significantly from usual practice in the UK? For example, did participants receive intervention (or comparison) condition in a hospital rather than a community-based setting?

2.10 Did the intervention or control comparison reflect usual UK practice?

Did the intervention or comparison differ significantly from usual practice in the UK? For example, did participants receive intervention (or comparison) delivered by specialists rather than GPs? Were participants monitored more closely?

3.1 Were outcome measures reliable?

Were outcome measures subjective or objective (eg biochemically validated nicotine levels + + vs self-reported smoking –)?

How reliable were outcome measures (eg inter- or intra-rater reliability scores)?

Was there any indication that measures had been validated (eg validated against a gold standard measure or assessed for content validity)?

3.2 Were all outcome measurements complete?

Were all or most study participants who met the defined study outcome definitions likely to have been identified?

3.3 Were all important outcomes assessed?

Were all important benefits and harms assessed?

Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?

3.4 Were outcomes relevant?

Where surrogate outcome measures were used, did they measure what they set out to measure? (eg a study to assess impact on physical activity assesses gym membership – a potentially objective outcome measure – but is it a reliable predictor of physical activity?)

(continued)

Appendix 2. Continued.**3.5 Were there similar follow-up times in exposure and comparison groups?**

If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison.

Analyses can be adjusted to allow for differences in length of follow-up (eg using person-years).

3.6 Was follow-up time meaningful?

Was follow-up long enough to assess long-term benefits or harms?

Was it too long, eg participants lost to follow-up?

4.1 Were exposure and comparison groups similar at baseline? If not, were these adjusted?

Were there any differences between groups in important confounders at baseline?

If so, were these adjusted for in the analyses (eg multivariate analyses or stratification).

Were there likely to be any residual differences of relevance?

4.2 Was intention to treat (ITT) analysis conducted?

Were all participants (including those that dropped out or did not fully complete the intervention course) analysed in the groups (ie intervention or comparison) to which they were originally allocated?

4.3 Was the study sufficiently powered to detect an intervention effect (if one exists)?

A power of 0.8 (that is, it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard.

Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate?

4.4 Were the estimates of effect size given or calculable?

Were effect estimates (eg relative risks, absolute risks) given or possible to calculate?

4.5 Were the analytical methods appropriate?

Were important differences in follow-up time and likely confounders adjusted for?

If a cluster design, were analyses of sample size (and power), and effect size performed on clusters (and not individuals)?

Were subgroup analyses pre-specified?

4.6 Was the precision of intervention effects given or calculable? Were they meaningful?

Were confidence intervals or p values for effect estimates given or possible to calculate?

Were CI's wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?

5.1 Are the study results internally valid (ie unbiased)?

How well did the study minimise sources of bias (ie adjusting for potential confounders)?

Were there significant flaws in the study design?

5.2 Are the findings generalizable to the source population (ie externally valid)?

Are there sufficient details given about the study to determine if the findings are generalizable to the source population? Consider: participants, interventions and comparisons, outcomes, resource, and policy implications.

Appendix 3. NICE guidelines for critical appraisal of qualitative studies.²⁹

1. Is a qualitative approach appropriate?

- Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings?
- Could a quantitative approach better have addressed the research question?

2. Is the study clear in what it seeks to do?

- Is the purpose of the study discussed – aims/objectives/research question/s?
- Is there adequate/appropriate reference to the literature?
- Are underpinning values/assumptions/theory discussed?

3. How defensible/rigorous is the research design/methodology?

- Is the design appropriate to the research question?
- Is a rationale given for using a qualitative approach?
- Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?
- Is the selection of cases/sampling strategy theoretically justified?

4. How well was the data collection carried out?

- Are the data collection methods clearly described?
- Were the appropriate data collected to address the research question?
- Was the data collection and record keeping systematic?

5. Is the role of the researcher clearly described?

- Has the relationship between the researcher and the participants been adequately considered?
- Does the paper describe how the research was explained and presented to the participants?

6. Is the context clearly described?

- Are the characteristics of the participants and settings clearly defined?
- Were observations made in a sufficient variety of circumstances?
- Was context bias considered?

7. Were the methods reliable?

- Was data collected by more than 1 method?
- Is there justification for triangulation, or for not triangulating?
- Do the methods investigate what they claim to?

8. Is the data analysis sufficiently rigorous?

- Is the procedure explicit – ie is it clear how the data was analysed to arrive at the results?
- How systematic is the analysis, is the procedure reliable/dependable?
- Is it clear how the themes and concepts were derived from the data?

9. Is the data 'rich'?

- How well are the contexts of the data described?
- Has the diversity of perspective and content been explored?
- How well has the detail and depth been demonstrated?
- Are responses compared and contrasted across groups/sites?

10. Is the analysis reliable?

- Did more than 1 researcher theme and code transcripts/data?
- If so, how were differences resolved?
- Did participants feed back on the transcripts/data if possible and relevant?
- Were negative/discrepant results addressed or ignored?

11. Are the findings convincing?

- Are the findings clearly presented?
- Are the findings internally coherent?
- Are extracts from the original data included?
- Are the data appropriately referenced?
- Is the reporting clear and coherent?

12. Are the findings relevant to the aims of the study?**13. Conclusions**

- How clear are the links between data, interpretation and conclusions?
- Are the conclusions plausible and coherent?
- Have alternative explanations been explored and discounted?
- Does this enhance understanding of the research topic?
- Are the implications of the research clearly defined?

Is there adequate discussion of any limitations encountered?**14. How clear and coherent is the reporting of ethics?**

- Have ethical issues been taken into consideration?
- Are they adequately discussed eg do they address consent and anonymity?
- Have the consequences of the research been considered ie raising expectations, changing behaviour?
- Was the study approved by an ethics committee?

As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)

Appendix 4. PRISMA Extension for Scoping Reviews Checklist

Section	Item	PRISMA-ScR Checklist Item
Title	1	Identify the report as a scoping review.
Abstract		
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.
Introduction		
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (eg, population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.
Methods		
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (eg, a Web address); and if available, provide registration information, including the registration number.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (eg, years considered, language, and publication status), and provide a rationale.
Information sources*	7	Describe all information sources in the search (eg, databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (ie, screening and eligibility) included in the scoping review.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (eg, calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).
Summary measures	13	Not applicable for scoping reviews.
Synthesis of results	14	Describe the methods of handling and summarizing the data that were charted.
Risk of bias across studies	15	Not applicable for scoping reviews.
Additional analyses	16	Not applicable for scoping reviews.
Results		
Selection of sources of evidence	17	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.
Characteristics of sources of evidence	18	For each source of evidence, present characteristics for which data were charted and provide the citations.
Critical appraisal within sources of evidence	19	If done, present data on critical appraisal of included sources of evidence (see item 12).
Results of individual sources of evidence	20	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.
Synthesis of results	21	Summarize and/or present the charting results as they relate to the review questions and objectives.
Risk of bias across studies	22	Not applicable for scoping reviews.
Additional analyses	23	Not applicable for scoping reviews.
Discussion		
Summary of evidence	24	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.

(continued)

Appendix 4. Continued.

Section	Item	PRISMA-ScR Checklist Item
Limitations	25	Discuss the limitations of the scoping review process.
Conclusions	26	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.
Funding	27	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.

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

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

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

‡ The frameworks by Arksey and O'Malley and Levac and colleagues and the JBI guidance refer to the process of data extraction in a scoping review as data charting.

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