

Gender and palliative care: a call to arms

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Abstract: There has been a systematic and largely unconscious neglect of gender in palliative care research, practice and policy. This is despite significant, although previously uncollated, evidence that gender influences almost all aspects of end-of-life preferences, experiences and care. The social situations of women, transgender people and men often differ from one another while also intersecting in complex ways with sex differences rooted in biology. If palliative care is to meet its aspiration of providing universal benefit, it urgently needs to address a range of gender inequalities currently (re)produced at the level of the laboratory all the way through to government departments. In this call to arms, we spotlight specific instances where gender inequalities have been documented, for example, regarding end-of-life caregiving, end-of-life intervention and palliative care access and benefit. We highlight how gender inequalities intersect with other social determinants of health including ethnicity and economic status to exacerbate situations of marginality. We conclude by offering some practical steps that can be taken to support the discipline to adopt a more critical gender lens to support more equitable research, policy and practice.

Keywords: end-of-life, gender, gender bias, inequalities, inequity, intersectionality, palliative care, social determinants of health

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Introduction

Health inequalities and the social determinants of health are not a footnote to the determinants of health. They are the main issue.¹

There is universal awareness of the importance of the social environment in determining our physical and psychological health. How long we live and what we die from are heavily influenced by the complex and intersecting ways in which this environment promotes, or constrains, our life circumstances. As such, the social determinants of end-of-life experience should be a major focus for palliative care. However, the opposite is in fact true. The biomedical paradigm within which the discipline is firmly anchored has led researchers and policy makers to search for universal truths about our dying which typically ignore social context.

In this discussion paper, we argue that this approach perpetuates ideas about managing death

and dying which serve the interests of those sectors of society with most power and further marginalise the interests of those with least. While there are many facets of social identity that need interrogating within a palliative care context – and their intersection must not be ignored as discussed further below – here we will focus predominantly upon the gendered nature of death and dying. We will argue that there has been a systematic and largely unconscious neglect of gender in palliative care research, practice and policy. This is despite significant, although previously uncollated, evidence that gender influences almost all aspects of end-of-life preferences, experiences and care. The social situations of women and men often differ and intersect in complex ways with sex differences rooted in biology. A nascent body of evidence about LGBT (lesbian, gay, bisexual and transgender) experiences of palliative and end-of-life care reports that transgender and non-binary people frequently experience discrimination on account of their gender status contributing to their lack of trust in palliative care services and their limited

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utilisation of advance care planning and hospice services.²⁻⁵ This limited body of evidence conducted primarily within a focus on sexual identity rather than gender and rarely with an exclusive focus on transgender and non-binary participants inhibits a comprehensive discussion of gender among this population.

We are going to focus, therefore, predominantly on cis women's experiences because, as is common within society as a whole, within palliative care research, practice and policy, cis women's experiences are much less visible than that of cis men. Moreover, we will demonstrate that the default palliative care 'patient' is imagined as being a man. However, we will also make visible ways in which differential treatment of men and women at end of life rooted in gender norms disadvantages men as well as women and transgender people. We argue that this must be recognised and acted upon if palliative care is to meet its aspiration of providing universal benefit. We will finish by providing some practical steps that can be taken to support the discipline to adopt a more critical lens.

What is the difference between 'sex' and 'gender'?

Gender is a shell game. What is a man? Whatever a woman isn't. What is a woman? Whatever a man is not. Tap on it and it's hollow. Look under the shells: it's not there.⁶

Crucial to comprehending how notions of gender affect palliative care is an understanding of the distinction between 'sex' and 'gender', a conceptual confusion not confined to palliative care but a feature of health-related research in general. An analysis of the use of these terms in 'gender specific medicine' – an emerging field that would be expected to have given the matter some thought – concluded that there was a 'conceptual muddle' in how they are understood and used. Nearly all the papers identified in a review of papers published in two foundational gender-specific medicine journals used the concepts interchangeably.⁷

The US National Institutes of Health (NIH) defines sex as 'biological differences between females and males, including chromosomes, sex organs, and endogenous hormonal profiles' and specifies that the terms 'male' and 'female' should be used to describe these biologically determined 'sex differences'.⁸ In contrast, the World Health

Organization (WHO) cautions against such a binary view of sex, indicating that 'the logic that female = 46XX chromosomes and male = 46XY chromosomes does not always hold, for every thousand births there are a few babies born with differently distributed chromosomes (sometimes referred to as intersex)'.⁹ Both NIH and WHO acknowledge the interaction between sex and gender. WHO states: 'biological sex and socially constructed gender interact to produce differential risks and vulnerability to ill health, and differences in health-seeking behaviour and health outcomes for women and men'.⁹

Gender is even harder to pin down. It is a term that refers to those roles and behaviours in society which are socially prescribed within a particular historical and cultural context and described using the terms 'man' and 'woman'. An often used example of gender norms is the designation of blue as a colour for baby boys and pink for baby girls – something which has nothing to do with biology and everything to do with how understandings of masculinity and femininity are constructed and evolve. In 19th-century England, pink was considered a masculine colour and blue a feminine colour; it was only in the 20th century that these meanings were reversed.¹⁰

The historical and cultural contextualisation of gender is further evidenced by the fact that not all cultures recognise only two genders. The Berdache in North America, the Fa'afafine in Samoa and the Kathoey in Thailand are just three examples of gender systems that accommodate gender identities beyond the woman/man dichotomy.⁹ The increasing recognition of transgender (people who identify with the gender other than the one assigned to them at birth) and non-binary people (who do not identify as women or men) also show how ideas of a binary gender system are also receding in contemporary Western societies.^{4,5,11}

While gender is a feature of our sociocultural context influencing, for instance, how we dress, talk and socialise, it also contains a performative aspect. Its power may best be demonstrated by offering examples of how people are judged for not successfully adhering to gender norms: a man's masculinity may be called into question for not playing sport. A woman may be deemed unfeminine for putting her career before wife and motherhood. A transgender person's gender might be challenged through the everyday experience of going into a public bathroom.

Such complexities are also evident when considering the impact of both sex and gender on end-of-life circumstances. Described as the health-survival paradox, women are more likely to live longer with a greater number of unhealthy life years, whereas men are more likely to die from fatal health conditions such as heart disease due to a mixture of biological and sociocultural lifestyle factors.^{12,13} Beyond this, both sex and gender influence many key aspects of our end-of-life experience and we discuss a few of these below, including caregiving, pain and fatigue, end-of-life intervention, access to hospice and specialist palliative care, and place of death.

Intersectionality

There is no such thing as a single-issue struggle because we do not live single-issue lives.¹⁴

While the focus of this discussion is gender, we must begin by acknowledging that an individual's experiences are shaped 'not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other'.¹⁵ The term intersectionality – based on the metaphor of an intersection – was coined by legal scholar Kimberle Crenshaw in 1991 to encapsulate this multidimensional understanding of identity.¹⁶ An intersectional mind-set directs researchers to consider how people navigate their agency in the context of multiple structures of power (patriarchy, colonialism, ageism, ableism) which then in turn shape their everyday activity and behaviour.¹⁵ Therefore, while gender is almost always a pronounced feature of end-of-life care, given the deep normative ideas surrounding 'care',^{17,18} – it is never the only factor at play.

For example, one of our studies that looked at the end-of-life preferences of people in advanced age included an indigenous cohort (for the first time), which illuminated the intersection between age and cultural identity within this context.¹⁹ We concluded that end-of-life preferences did differ by gender, but that these differences were culturally contingent. More older Māori women wanted spiritual practices at end of life than older Māori men. In addition, more non-Māori men wanted to be resuscitated than non-Māori women.

It is beyond the scope of this article to interrogate all the ways in which gender intersects with other social axes of potential marginalisation and so we

provide one example below related to an issue which is (fortunately) receiving increasing attention within the palliative care literature – namely, the relationship between poverty and end-of-life circumstances. We outline how an intersectional lens can effectively integrate the interconnected impact of gender, class and ethnicity and can be utilised in future research to extend to other social factors such as disability, age, mental health and sexual orientation.

Sex, gender and caregiving at end of life

Biologically, women are the nurturers. That's good because the caregiving role is more natural to [a wife caregiver]. That's bad because she isn't even considered a caregiver. It's expected of her – she's just doing what a wife is supposed to do.²⁰

When considering the gendered nature of end-of-life experience, caregiving is a good place to start. Universally, most caregivers are women. A recent US survey concluded that upwards of 75% of all caregivers are women and women spend 50% more time providing care than men.²¹ In Cuba and Venezuela, 81% of caregivers of people with dementia are women.²² Women caregivers also undertake more intense and more intimate caring tasks and are less likely to seek and accept formal support.²³ There is a relative dearth of population-level data that provides the breakdown of the number of end-of-life caregivers by gender. However, a recent cohort study of UK primary care database of 13,693 bereaved cohabitantes (aged 60 and above) found that two-thirds of their sample were women, suggesting these gendered patterns continue at end of life.²⁴

It is not controversial to say that women's caring work is largely invisible and economically undervalued. Marilyn Waring, an academic and politician from Aotearoa New Zealand, argues that 'the success of the global economy rests on women's unpaid work and on the environment – yet both are systematically ignored and undervalued by conventional economic measures'.²⁵ The economic invisibility of women's caring work both reflects and reinforces gendered understandings of caring as a 'natural' role for women. A recent blog in *YourHealthJournal.com* by Dr Diana Denholm about caregiving within the context of terminal illness, from which the introductory quote to this section was taken, demonstrates the extent to which this socially constructed idea has

become naturalised and normalised.²⁰ A widespread example of this is the belief reproduced in research and policy that care for dying family members is a normative duty.²⁶ Without unpacking the gendered impact of ‘duty’, which falls disproportionately on women, such caregiving ‘evidence’ reproduces gender inequities.^{27,28}

There is evidence that doing ‘what a wife is supposed to do’ can carry significant responsibilities within a heteronormative end-of-life context for some women. It is not just expected that a wife will provide care but will provide a certain type of care which will realise a husband’s vision for a ‘good death’. For example, there is increasing evidence that achieving a home death is coming to be regarded as a mark of caregiving ‘success’. Not achieving this outcome can result in guilt, feelings of failure and complicated grief.^{29–31} A qualitative study exploring the experiences of 13 ‘female’ and 5 ‘male’ caregivers in Canada found that not keeping a promise to achieve a home death could result in long-term negative consequences. One participant talked about her feelings of failure: ‘I felt like I failed him. I still feel that way. We’ve been together almost, well, 49 years. And the one thing, I mean he didn’t ask much of me, and I couldn’t do it [softly crying]’ (70 years, female).³² While gender was not a specific focus of analysis – in line with most caregiving research in palliative care²⁷ – the gender difference in caregiver participants is reflective of the literature; all quotations highlighting the association between home dying and caregiver ‘success’ were from women.

Health care professionals have a role to play in this gender stereotyping too. A recent Canadian qualitative study of hospice at home, written from the perspective of nurses, dying people and their family carers, found that nurses tend to operate from the assumption that wives and daughters need less help caring than husbands and sons. In doing so, they implicitly support pre-existing gender norms by offering men more help than women.³³ Gender norms are frequently reinforced, often unthinkingly, on women by other women.

This obviously does not mean that men do not provide care. Rather, perceptions of men caregivers, their transition into caregiving and the support they receive when caregiving differ. The man who cares for his dying wife is viewed similarly to the man who cares for his young child – as someone doing something potentially heroic, as it is not seen as aligning with his socially ascribed

gender role.³⁴ This is reflected in the evidence that shows men caregivers receive more support than women caregivers.³⁵

Such gender norms may also help explain why women who are caregivers report higher levels of physical and psychological health problems, including stress, anxiety and depression, when compared with men who are caregivers.^{23,36,37} There is also mounting evidence that these psychological and physical health effects intersect for women in ways related to both sex and gender, providing some explanation for the poorer health outcomes reported by caregivers. For example, a study among 239 postmenopausal, non-smoking, disease-free women found that accumulation of major life stressors across a one-year period predicted telomere attrition over the same period.³⁸ For every major life stressor that occurred, there was a significantly greater decline in telomere length. This matters because telomere shortening is associated with many health conditions, including dementia and heart failure.³⁹

However, it is important to remember that patriarchal gender norms do not only negatively affect women. Men are less likely to report emotional concerns, such as stress, anxiety and depression, than women.³⁷ Therefore, their psychological concerns, as ‘carers’ and ‘patients’, are likely to be underreported at end of life. Aptly illustrating this, a 2005 US-based telephone survey study of 1384 caregivers (29% were men) concluded from linear regressions of quantitative data that men experienced lower caregiver strain.⁴⁰ Through their subsequent qualitative analysis of their participants’ free-text comments, however, the authors indicated that the cause of this observed disparity appeared to have more to do with men’s reluctance to discuss their experiences of distress (using fewer words and rarely offering unsolicited instances of struggle) as opposed to them actually experiencing lower levels of distress. Such a finding confirms that gender norms around men’s expression of emotion can have a detrimental impact, for example, by making them reluctant to access available supports.

Women’s symptom experience at end of life

Pain

Pain is real when you get other people to believe in it. If no one believes in it but you, your pain is

madness or hysteria or your own unfeminine inadequacy. Women have learned to submit to pain by hearing authority figures – doctors, priests, psychiatrists – tell us that what we feel is not pain.⁴¹

Pain management is a significant focus for palliative care research and practice, yet little attention has been paid to either sex or gender in relation to pain.⁴² To provide one example, a recent systematic review to identify the ‘prevalence of pain in patients with cancer’ specified reporting pain by ‘sex’ as an inclusion criteria.⁴³ However, no difference in pain prevalence by sex was reported, nor was sex/gender interrogated as a predictor of pain. Differences in prevalence of pain between prostate (lower) and breast cancer (higher) were presented, but their association with sex/gender was not discussed. Similarly, the implications of emerging data regarding gender and sex differences in response to opioid therapy for pain have not been considered within a palliative care context.⁴⁴ Given the centrality of effective pain management to palliative care, we believe interrogating gender as a determinant of both pain experience and pain management must be prioritised in future research. We therefore provide a brief overview of the gendered nature of pain below.

There is a long history of women’s pain being dismissed which continues to this day.⁴⁵ There is substantial evidence that the prevalence of most common forms of pain is higher among women than men.⁴⁶ Women also report greater pain after invasive procedures than men.⁴⁶ This is likely to be why women’s pain is underestimated compared with that of men,⁴⁷ meaning that women receive less analgesia,⁴⁸ are more likely to have their pain attributed to psychological rather than medical causes⁴⁹ and to be prescribed sedatives rather than pain relief. It is also important to remember that women are diagnosed with more chronic pain-causing conditions than men, including many musculoskeletal or inflammatory conditions;⁴⁷ pain-causing conditions such as endometriosis and vulvodynia are also only experienced by women. An individual’s history of experiencing pain is likely to affect their end-of-life pain experience.⁵⁰ That this history will be different for women is therefore important to recognise.

In addition, there is significant evidence to indicate gender bias in pain management. For example, an early study found that women in the United States were only half as likely to be prescribed painkillers after coronary bypass surgery

when compared with men.⁵¹ Another US study found women wait on average 65 minutes before receiving an analgesic for acute abdominal pain in the ER compared with only 49 minutes for men.⁵²

There is also evidence from recent research that men’s pain is taken more seriously than that of women. A video-based study of simulated patient cases undertaken with 34 specialist pain doctors and 29 medical students explored prescribing decision-making for chronic pain.⁴⁹ The authors concluded that there was a ‘distinct gender difference’ in the relationship between ratings of expression of pain and actual pain estimates:

In men they were unrelated, even for those rated as likely to be exaggerating pain. For women, the higher the rated likelihood of exaggeration, the lower the pain estimate. It is not clear whether this difference is itself further gender bias – that even when men are thought to exaggerate pain, it remains credible and is not discounted – or whether there is another explanation that requires specific investigation (p. 17).

There is also a complex intersection between sex and gender responses to pain that indicates we need to think about biology as well as social conditioning. For example, basic science research on rodents has identified sex differences in pain processing, including in opiate receptor density, functioning and circuitry.⁵³ Opiates are one of the most commonly administered drugs to relieve pain at end of life and therefore this finding has important implications for palliative care. However, interrogating this relationship further is difficult because 80% of research is undertaken with male mice and rats, as they are viewed to be less ‘troublesome’.⁵⁴ The ‘trouble’ caused by female animals stems from their ovaries, which are perceived to make data from female animals ‘messy’. As Shansky⁵⁵ argues, this viewpoint not only negates the role hormones have on male physiology but also plays to ‘one of the most deep-seated misconceptions about the human psyche’, namely ‘that men are simple and women are complicated’. Beery and Zucker’s⁵⁴ review identified that this sex imbalance persisted across physiology, pharmacology and endocrinology and was most marked in neuroscience, with almost six times more male animals than female animals used in animal research.

Such an imbalance is something we should all be worried about – particularly if we are

women – because clinical practice is underpinned by basic science such as this. Ultimately it means that our understanding of disease processes, and their management, is largely informed by male biology; it is only within the last couple of years that funders in the United States and Europe have required researchers to use both female and male animals. Indeed, increased recognition of the importance of sex in biomedical research has prompted efforts to encourage researchers to consider sex in their research designs,⁵⁶ although gender has been largely overlooked,⁵⁷ and the confusion between sex and gender persists. A review of the journal *Pain* identified that the terms sex and gender are employed interchangeably and inaccurately, with three quarters of papers using the term gender to refer to sex differences.⁵⁷

Fatigue

All the women in me are tired.⁵⁸

The first study of fatigue and quality of life in palliative care concluded that, among people with advanced illness receiving palliative care at home, women experienced both a higher prevalence of fatigue and greater fatigue severity.⁵⁹ The difference was maintained over the three-month study period and was not explained by baseline differences in performance status, depression or quality of life. The conclusion was that these findings were ‘largely unexplained’. However, no reference was made to the fact that in general population studies, women consistently report higher levels of fatigue than men. A recent Swedish study, for example, reported a gender difference in fatigue consistent with previous international evidence, concluding that ‘Older, highly educated, physically active men, with little sedentary behaviour are generally the least fatigued’.⁶⁰ They comment on the intersection between gender and socioeconomic status in fatigue experience as follows:

Perhaps fatigue is a bodily expression of ill-being, which is related to other health inequities, economic factors and unequal assets in life. Fatigue might enhance health inequities further, since women in the lowest socioeconomic class are more prone to feel fatigued and therefore might be less likely to be physically active.

Another factor might be related to the fact that caring and household responsibilities of women

do not end with the diagnosis of a life-limiting illness. For example, evidence suggests that women, but not men with dementia, continue to undertake a large amount of cleaning and food preparation in accordance with the pre-diagnosis distribution of household tasks.^{61,62} Another study highlight how wives with functional or cognitive impairment continue to perform health-promoting behaviour such as monitoring their partners’ symptoms (again something not observed in the reverse).⁶³ Might these factors contribute to the ‘largely unexplained’ high levels of fatigue women are reporting at the end of life? And is it because fatigue is experienced more by women than men that it is one of the most under-researched symptoms in palliative care?

Gender and hospice and specialist palliative care

Males and younger patients who received EPC [Early Palliative Care] had better QOL [Quality of Life] and mood than those who received oncology care alone. However, these outcomes did not differ significantly between treatment groups for females or older patients.⁶⁴

US-based research has consistently found that women are more likely than men to be enrolled in hospice which is seemingly related to both provider and patient bias.^{65–69} Saeed and colleagues⁶⁷ found that, among 383 patients with metastatic cancer, women were three times more likely than men to consider palliative care, even when controlling for disease factors, age, race, education and financial strain. The study authors explained the results as follows:

there is a societal norm that men are supposed to be tough and invulnerable and there is a lot of vulnerability in seeking help and focusing on comfort care instead of always being in fighter mode. Men are out to ‘beat the cancer’, and some may perceive palliative care as giving up.⁶⁷

Gender norms therefore shape many men and women’s perceptions on how they ought to act in the face of illness, in turn shaping what care they receive.⁴⁵

But who benefits from palliative care? Globally, there are efforts to support early palliative care integration into the care and treatment of people with life-limiting illness.⁷⁰ This is based on

evidence that such integration can not only improve quality of life but also improve survival. But what we have not heard is that it is men – not women – who reap these benefits. While the original Temel study⁷¹ is well-known – a Google Scholar search in July 2020 revealed it had received almost 5700 citations – a secondary analysis by gender of the same data shows that women do not benefit from early integration in the same way.⁶⁴ By July 2020, this article had only received 29 citations. Furthermore, new clinical guidelines and policies are advocating for early integration of palliative care with no acknowledgement of differential impacts for women and men.⁷² For example, the first recommendation of the American Society of Clinical Oncology Clinical Practice Guidelines Update is that:

Patients with advanced cancer should be referred to interdisciplinary palliative care teams (consultation) that provide inpatient and outpatient care early in the course of disease, alongside active treatment of their cancer (type: evidence based, benefits outweigh harms; evidence quality: intermediate; strength of recommendation: strong).

No mention is made of gender.

Women and end-of-life intervention

Older women do not have the same end-of-life choices as men. Gender colours beliefs regarding care and treatment, as well as decisions made by clinicians in healthcare settings. For example, in a study we conducted a few years ago, we found that the women's views about the choices they had within the context of advanced care planning were deeply influenced by gender.⁷³ As one participant noted, 'it is the wife who has to look after the husband – not the other way around'. Her perspective echoed the other women's views that they would be expected by family to provide care, or else be viewed as failing in their role. However, their views were also influenced by their gendered assumption that men could not be relied on to care because it is not in their nature.

Many studies have shown that women are less likely to state a preference for life-extending treatment than men, with motivation seemingly related to fears of being a burden.^{66,74–78} Such a preference aligns with their end-of-life experiences; the evidence indicates that women are less likely to receive life-extending treatment. For example, women with cancer are more likely to

have early do-not-resuscitate (DNR) orders written during hospital admission than men.⁷⁹

Among 353 patients with metastatic cancer, men were more likely than women to receive 'aggressive, non-beneficial' intensive care unit (ICU) care at end of life, although those who reported an end-of-life discussion were less likely to have an ICU stay than those who did not. Interestingly, this association did not hold for women.⁸⁰

There is also evidence from the United States that men are more likely than women to receive chemotherapy within 14 days of death and are less likely to receive hospice care; older age, being 'non-white', and being unmarried, also predicted aggressive end-of-life care.⁸¹ In a US tertiary cancer centre, women had significantly less hospital admissions than men.⁸² Similarly, Miesfeldt and colleagues⁶⁶ reported that in a US cancer sample, female gender was associated with being less likely to receive aggressive care and to experience late hospice enrolment. In a Belgium study of end-of-life decision-making, family discussion of pain and symptom treatment with the family occurred significantly more often with women patients than men patients and palliative care clinicians were consulted more significantly in cases of euthanasia in women than in men (70.4% *versus* 37.2%).⁸³

Gender and place of death

In most countries more men than women die at home (in the UK 22% *versus* 16%) and more women than men die in care homes (in the UK 21% *versus* 10%).⁸⁴ There are a number of factors implicated in this trend. While women live longer compared with men, they live a higher proportion of years with disabilities⁸⁵ and experience approximately twice as many years of cognitive impairment.⁸⁶ Within a heteronormative context, women are therefore more likely than men to outlive their spouse to whom they are likely to have provided care, and not to have a partner to care for them. There is also evidence that people who have been carers – predominantly women as discussed above – are less likely to express a desire to die at home than those without previous caring experience. This appears to be related to understanding the realities of what is involved in supporting someone to die at home and not wanting to be a burden to adult children.¹⁹ Overall, these data indicate that, while women provide the majority of care across their lives, they are often

left without the reciprocal level of care at their own end of life.

Home dying is also known to affect the home space⁸⁷ – for example, medical equipment can render it ‘hospital like’⁸⁸ – but there has been little exploration of the extent to which this impact is gendered. Exploring this further would be interesting given the designation of the home as a ‘woman’s space’ within most cultures⁸⁹ – a site where complex intersections of power and gendered roles play out. For some women home is a place of autonomy, but also work. For others it is a site of oppression and violence: on average, two women every week across England and Wales are killed by a current or former partner⁹⁰ and in Aotearoa New Zealand police investigate a case of domestic violence every five minutes.⁹¹

An intersection example: gender and poverty

Most of the poor people in the world are women. In no country on earth are women economically equal to men.⁹²

As we argue above, taking a single issue approach to understanding end-of-life circumstances is flawed. Rather, we advocate for the need to recognise intersecting axes of oppression and privilege. Below we provide an example in relation to a research area which is gaining increased attention within a palliative care context, namely the impact of socioeconomic circumstances at end of life. We explore both gender and ethnicity/cultural identity and point to how analyses should also be extended to other social factors.

Older women are significantly more likely than older men to be living in poverty due to a lifetime of lower pay and unequal working conditions.⁹³ In India, 60% of older women have no assets in their name. In the United States, women represent two-thirds of older people living in poverty and Black and Hispanic women are two to three times more likely to be living in poverty than White women. In Australia, women aged 55 and above are the fastest growing cohort of homeless Australians, increasing by 31% between 2011 and 2016.⁹⁴

In most countries – even economically resource-rich countries – this situation is getting worse. In the United States, the life expectancy of women is declining sharply.⁹⁵ In the United Kingdom, the

2020 Marmot report concluded that austerity had ‘cost the UK a decade’ and women have been particularly affected. The role of the COVID-19 pandemic in exacerbating economic – and gender and racial – inequities has also been identified.⁹⁶ It is therefore more pressing than ever to address the question of how feminisation of poverty plays out at end of life.

We could identify no previous research which has addressed this question directly, but emerging evidence does confirm the significant impact of poverty – more likely to be experienced by women than men – and more likely to be experienced by transgender people (of all sexual orientations) than cis people – on end-of-life circumstances.⁹⁷

For example, people living in areas of deprivation have reduced access to specialist palliative care services⁹⁸ and are less likely to die in a hospice.^{84,98–101} People living in deprivation are also less likely to die at home¹⁰² and more likely to die in hospital and alone.¹⁰³ Hospices can be perceived as resources for White, middle-class populations and evidence from our work in Aotearoa New Zealand indicates that palliative care services are not always congruent with the needs and aspirations of structurally disadvantaged populations, notably indigenous Māori.^{104–107} Similarly, hospices tend to be located in more affluent areas reflecting their charitable origins.^{105,108} Finally, the promotion of home dying in palliative care policy assumes people live in housing which can support a good end-of-life experience and have family and whānau who are willing and prepared (including financially prepared) to provide care.¹⁰⁹ In many countries, including New Zealand, the inadequate nature of the housing stock and links with reduced health outcomes are well established.¹¹⁰ Vulnerably housed – and homeless – people experience particular challenges at end of life,¹¹¹ although it must be noted that people in this situation ‘are not passive victims of vulnerability, but [are] highly resilient’.

This brief interrogation of poverty and palliative care highlights one potential axis of intersection. However, to truly understand individual experience, a much broader lens is required. There is evidence, for example, that people who live with disabilities and serious mental health problems experience higher levels of poverty than the general population.¹¹² How this then intersects with gender and end-of-life experience is unclear.

Future directions

The history of men's opposition to women's emancipation is more interesting perhaps than the story of that emancipation itself.¹¹³

We finish this article with some recommendations as to how palliative care can attend to gender as a key social determinant of dying. Ultimately, we want to advocate for a paradigm shift within the discipline such that consideration of sex and gender – alongside, and in intersection with, other social determinants of dying – becomes normal practice whether your research is in a laboratory or within a community. The first step to initiating change at this scale is convincing *all* researchers that this is necessary. This may be more challenging than it first seems as Kelli Stajduhar argues in her eloquent discussion of privilege in palliative care. She quotes Denise Hess, a palliative care chaplain in the United States who writes, 'privilege is as invisible as air unless you don't have it and want to breathe'.¹¹⁴ Similarly, Peggy McIntosh argues, people privileged by virtue of social factors, such as gender, find it difficult to recognise that privilege even when it is pointed out to them. However, more positively she notes that: 'privilege can also be leveraged to mobilize positive change, to lift people up to find solutions that work for them'.¹¹⁵

As we have demonstrated, any commitment to the sex and gender-blind nature of the status quo within palliative care is disadvantaging to everybody, regardless of gender identity. Palliative care prides itself on a commitment to realising the end-of-life experience of each individual. We strongly believe this cannot happen unless our call to attend to gender in palliative care research, practice and policy is both heard and acted upon, and we provide some concrete examples below of how this can happen below.

Recommendations for research

There is an urgent need for research attending to the gendered nature of end-of-life experience and treatment. We have clearly highlighted a need to focus on gender both as a discrete field of inquiry and as a factor affecting all aspects of palliative and end-of-life care. To explore all possible opportunities is beyond the scope of this article, but below we identify one question for each of the issues we discussed above which we believe represents a priority for future research. As explored

above, each needs to be addressed through an intersectional lens:

- What are the experiences – and expectations – of non-binary and transgender people regarding palliative and end-of-life care?
- How does gender influence expectations about caregiving for people with life-limiting illness and their family and professional caregivers?
- How does the gendered nature of common end-of-life symptoms such as pain, fatigue and nausea throughout the life-course influence end-of-life symptom experience?
- What are the reasons for the observed association between early palliative care intervention and benefit for men, but not women?
- What are the reasons for the observed association between level of end-of-life intervention and gender and to what extent do they correspond with individual preferences for end-of-life care?
- How does gender influence the likelihood that advance care planning results in an end-of-life experience in line with an individual's preferences?
- How do gendered understandings of home influence preferences for, and the experience of, receiving end-of-life care and dying at home?

Integrating gender into existing research must also be a priority. This includes the following:

- Ensuring gender is a focus for analysis in systematic reviews of the literature on all topics, highlighting differences by gender and making visible where this information is not available. Moving beyond merely observing gender and sex differences to interrogating and theorising identified disparities.
- If gender is a specific focus of a literature review, consider applying the Feminist Quality Appraisal Tool which we developed for use, not just in palliative care research but in public health research more broadly¹¹³ to support researchers to interrogate existing literature through a feminist lens.
- Consider using a checklist which is sensitive to gender when planning and reporting research. Although none specific to palliative care currently exist, the SAGER

checklist – which was designed to be applicable across all health-related disciplines – provides a good starting point.^{114,115}

- A more sophisticated gender analysis would move to also attend to issues of power and intersectionality, as well as provide clear recommendations for the nature of the changes needed to promote gender equity in end-of-life experience.
- Research involving animal models relevant to palliative care drug therapies must include female and male animals; the sex of animals, and differences between sexes in drug response and side effects, should be reported.

Ensuring greater sensitivity to gender in palliative care research will also require support from journal editors and funders. Progress is being made in this area in health research generally, although there is still a way to go. For example, a recent review of official statements about sex/gender inclusion from 45 national-level health funding agencies across 36 countries and across 10 top-ranked ‘general health’ journals concluded that:

(a) there is no consistency in whether sex/gender are mentioned in funding and publishing guidelines; (b) there is wide variation in how sex/gender are conceptualized and how researchers are asked to address the inclusion/exclusion of sex/gender in research; (c) funding agencies tend to prioritize male/female equality in research teams and funding outcomes over considerations of sex/gender in research content and knowledge production; and (d) with very few exceptions, agency and journal criteria fail to recognize the complexity of sex/gender, including the intersection of sex/gender with other key factors that shape health.¹¹⁶

- We therefore recommend that journal editors and funders in palliative care review their guidelines to ensure sex/gender is appropriately attended to and included within palliative care research and their intersection with other key factors that shape health is acknowledged.
- Researchers should also reflect on gender (and other forms of) diversity within their teams.
- Conference organisers need to ensure gender (and other forms of) diversity in presenters and panel members.¹¹⁷
- Men need to support efforts to better attend to gender, for example, by refusing to sit on ‘manels’ (men-only panels).

Recommendations for practice and policy

We have provided numerous examples of the way in which policy and practice that is gender-blind serves to perpetuate patriarchal gender norms to the disadvantage of men, women and transgender people. Tackling gender equity involves making visible, and seeking to challenge, these norms wherever possible and in ways that attend to intersecting axes of oppression. We also need to focus on system-level change rather than merely individual change and stop perpetuating universal ideals – for example, regarding a ‘good death’ – without critical consideration of how universally achievable they are.

A good example is provided in thinking about the uncritical assumption in palliative care policy internationally that end-of-life care ‘in the community’ is both desired and achievable for all.¹⁰⁹ We agree with Sutherland and colleagues²⁸ assertion that such an approach is primarily grounded in neoliberal discourses of individualism, framing care as something outside of the market and state responsibilities. It promotes a notion of communities as homogeneous and conflict-free – which any basic intersectional analysis of, say, the recent UK election would show as untrue. It also overlooks the fact that in this context, care still falls disproportionately to one or two individuals – who are most likely to be women – to provide care. Felicity Aulino working in the Thai context argues that policy drives such as ‘care in the community’ result in ‘structural violence’ by obscuring the degree of care provided by women relatives for particular individuals as well as morally emphasising that such women ought to be providing care for others too.¹¹⁸ The failure to include family – or ‘informal’ caregiver costs in palliative care economic analyses – further obscures, and devalues, women’s work.¹¹⁹ We are hoping that a new European Association of Palliative Care taskforce focused on the economic costs of family caregiving will help develop a new evidence base where these costs are captured and made visible to policy makers.¹²⁰ Finally, we hope that the increasing application of a public health lens to palliative care research, as well as practice and policy, is likely to help greater attention to the social determinants of dying. As Grindrod recognises, ‘Inherent in a public health perspective is the recognition that individuals are not solely responsible for the status of their health’.¹²¹ However, to date, there has been little gendered analyses of concepts such as ‘compassionate communities’ and attention will need to be paid to ensuring ‘community’ does not equal ‘women’s work’.

It is important that clinicians reflect upon the gendered assumptions they bring to their interactions with patients. There is significant evidence that these result in men and women receiving different care at end of life as noted above, which is to be expected as clinicians – like everyone else – are a product of a society which treats men and women differently. The challenge for all of us is to recognise these assumptions as they arise. As one responder to a blog we wrote said:

I am a palliative care doctor and lead multidisciplinary team meetings. I caught myself asking on more than one occasion when planning for discharge home, ‘Does Mrs X have any daughters’, Really a shockingly sexist thing to say ...¹²²

We urge other clinicians to similarly challenge their assumptions.

Conclusion

In this article, we have argued for a paradigm shift in palliative care research, practice and policy to incorporate a focus on gender whether our workplace is a laboratory or a community, a hospital or a government department. We have also argued the need to recognise that gender is something which is performed, and always adopt an intersectional approach, ensuring we do not promote the interests of White, middle-class cis women to the detriment of others. There is also an urgent need to consider how gender operates beyond a binary system by foregrounding the experiences of transgender, non-binary and intersex people’s experience of end of life. Continuing to be gender-blind, which perpetuates the White, middle-class man’s experience as the ‘objective’ norm, ultimately takes us further and further away from ensuring we all contribute towards equity-focused palliative care.

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