

# Utilising literature and systems theory to explore the intersections between policy, practice and equity of access to palliative care for older adults in Aotearoa New Zealand

Dallace Lilley<sup>1</sup> and Kate Reid<sup>2</sup>

<sup>1</sup> Hospice Marlborough, Aotearoa New Zealand

<sup>2</sup> Faculty of Health, University of Canterbury, Aotearoa New Zealand

## ABSTRACT

**INTRODUCTION:** Older adults are the 'disadvantaged dying' within palliative care (Gott et al., 2011). International and national research indicates older adults experience inequity of access to inpatient and outpatient palliative care.

**APPROACH:** Undertaking post-graduate study allowed exploration of older adults' experiences of inequity observed in practice, particularly how access to resources could change a person's end-of-life choices or impact the capacity for a family to care for loved ones at home. This article examines the intersections between policy and palliative care practice, ageism and inequity experienced by older adults, including Māori and LGBTQ+ perspectives, and older adults' caregivers, family and whānau.

**CONCLUSIONS:** A social work lens has enabled exploration of the impacts of inequity and ageism within academic literature, strategic documents, and legislative frameworks to advocate for older adults within palliative care services. Research advocates for age-attuned policy development and specialist education for palliative practitioners as the way to effectively disrupt age-related inequity and improve outcomes for older adults within palliative care services.

**Keywords:** Older adults; equity; palliative care; systems theory; social work

## Demographic implications and inequity

Approximately 1.2 million people in Aotearoa New Zealand will be aged 65 years and older by 2034, constituting over a fifth of the total population, almost 180,000 people aged 85 years and older will be amongst those experiencing longer and healthier lives (Jackson & Healthwatch, 2019). Alongside celebrating longevity, it is important to consider the implications this poses for age-attuned policy and research development;

this includes rethinking existing perceptions of ageing, how society views older adults and how these perceptions effect older adults' end-of-life care (Frey et al., 2020; Gott et al., 2017; Jackson & Healthwatch, 2019; Murray et al., 2017).

Older adults would benefit from specialist palliative care across their illness trajectory, yet older adults' psychosocial, physical, and psychological/emotional needs are marginalised within national and international palliative care strategies,

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**CORRESPONDENCE TO:**  
Dallace Lilley  
dallace.lilley@mht.org.nz

academic literature, and research (Frey et al., 2020; Murray et al., 2017). Within the research, inequity within palliative care is related to ageism, including a lack of integration between palliative care and gerontology, and incorporating theoretical frameworks that explore older adults' perspectives, needs and aspirations (Gott et al, 2011; Nicholson & Richardson, 2018).

### Social work perspectives

As a palliative care social worker within a hospice multidisciplinary team (MDT), the first author primarily works alongside patients who are older adults, their family, whānau, and caregivers. Undertaking post-graduate study allowed exploration of older adults' experiences of inequity observed in practice, particularly how access to resources could change a person's end-of-life choices or impact the capacity for a family to care for loved ones at home.

From early professional beginnings until the present day, social work theories are recognised for responding to well-being and health disparities within society by exploring the connections between inequality and oppressive social structures (Beddoe, 2011). Social work practice is committed to responding to inequity and empowering positive change for marginalised populations through person-centred, inclusive, multidisciplinary, interdisciplinary, and collaborative practice approaches (International Federation of Social Workers [IFSW], 2021). Social work contributions are pivotal to achieving age-attuned care and equitable palliative care outcomes for older adults.

Social work practice, values and skills, ideologies, and knowledge bases, including holistic assessments, care coordination, continuity of care and patient-led therapeutic relationships, are conversant with age-attuned policy development (Connolly & Harms, 2015; Egan & Maidment, 2016; Golden, 2019; Nicholson & Richardson,

2018). Palliative care social work responds to social and psychosocial needs, and provides specialist knowledge of trauma-informed care, and grief and loss experienced across the lifespan (Connolly & Harms, 2015; Egan & Maidment, 2016; Golden, 2019; Payne, 2004). Current research acknowledges social work's commitment to anti-oppressive practice and identifies social work practitioners as being ideally situated to effectively advocate for equitable palliative care outcomes for older adults (Aotearoa New Zealand Association of Social Workers [ANZASW], 2019; Golden, 2019; IFSW, 2021; Wang & Wang, 2020). However, disrupting inequitable access to palliative care for older adults can be a contentious space as social work contributions are often marginalised when a medical model is adopted by MDT.

The "Hidden in Plain Sight" report (Hogan, 2021), acknowledges the privileging of medical practitioners within Aotearoa New Zealand healthcare and advocates for reducing medical model dominance through direct access to allied health professionals, including social workers. Empowering the role of social work within palliative care practice and policy development can improve outcomes for older adults by reducing inequities between allied health and medical model practitioners. Social work representation within hospice MDT can reduce reductionist pathology and medical-model dominance (Agnew et al., 2011; Golden, 2019; Hogan, 2021; Payne, 2014; Wang & Wang, 2020).

### Systems theory practice frameworks

Social work operates across all social sectors to understand and respond to inequity. Practitioners will often critically engage with policy and practice utilising systems theory frameworks (Connolly & Harms, 2015; Egan & Maidment, 2016; Payne, 2014). Systems theories consider how inequity issues, and the ability for a person, family, whānau or community to cope and adapt during

adversity, is impacted by societal systems that either detrimentally affect, or positively empower, autonomy and choice (Connolly & Harms, 2015; Payne, 2014). There are limitations with the broadness of systems theory analysis, including revealing multiple interventions, such as policy development at national levels or at interpersonal levels within practice, that can problematise identifying the most appropriate or effective option (Connolly & Harms, 2015; Payne, 2014).

Systems theories view adversity experienced by individuals, family, whānau and communities as social issues (Cheyne et al., 2011; Payne, 2014). Understanding oppression as a social issue underpins strengths-based, anti-oppressive social work values and skills (Egan & Maidment, 2016; Payne, 2014). Oppression can be experienced at multiple levels, including cultural, structural, and interpersonal oppression. Within palliative care, oppression can manifest as deficit pathology, viewing patients as *sites of disease*, and reductionist approaches that minimise responding to emotional and spiritual distress (Giles, 2016; Payne, 2014; Thompson, 2016).

Systems theories interconnects social systems, and resource constraints to older adults' inequity of access to palliative care by illuminating the effects of loss of agency and self-determination to a person's ability to achieve a *good death* (Nicholson & Richardson, 2018; Payne, 2014; Rosa et al., 2022). Systems perspectives consider these interconnections within a chronological time and a place. Currently, Aotearoa New Zealand's political system is predominantly *third way*. Third-way policies promote the outsourcing of social services to community organisations to minimise government interventions and expenditure, often without adequate funding and resources to achieve optimum care (Cheyne et al., 2011; Connolly & Harms, 2015; Payne, 2014). Home-based care is an example of outsourcing and service shortfalls creating inequity as family and whānau often

bridge the gaps within service delivery by providing unpaid care (Cheyne et al., 2011; Dunbrack, 2005; Wong et al., 2022).

Inequity of access to palliative care for older adults is exacerbated by Covid-19-related resource deficits including service provider staff attrition, and restricted access to hospices and hospitals (Payne, 2014; Powell & Silveira, 2021). Inequity occurred prior to Covid-19, with observations from practice identifying inadequate staffing for home-based agency supports restricting older adults' ability to choose to die at home. Hospice, and aged residential care (ARC) vacancy deficits have further restricted patients' ability to receive specialist end-of-life care outside of a hospital setting (Payne, 2014; Powell & Silveira, 2021). Covid-19 exposed existing resourcing and policy deficits and has highlighted a need for robust, age-attuned policy development (Gott et al., 2017; Nicholson & Richardson, 2018; Payne, 2014; Rosa et al., 2022).

### Age-attuned care

Nicholson and Richardson (2018) maintained that *age-attuned* policy frameworks empower accessible, appropriate care for older adults by reducing age-related inequities. Age-attuned hospice policy development empowers older adults' equity through the provision of integrated, strengths-based care (Durie, 2011; Nicholson & Richardson, 2018; Payne, 2014; Rosa et al., 2022). Age-attuned practice is relational and achieves wrap-around holistic care by considering the relationships between a patient, their caregivers and whānau. This is achieved by harnessing whānau strengths when identifying care goals that reflect older adult patients' unique needs and aspirations (Nicholson & Richardson, 2018). Age-attuned care acknowledges older adults as the experts in their own lives; this can effectively reduce practitioner dominance within palliative care services (Egan & Maidment, 2016; Nicholson & Richardson, 2018; Payne, 2014).

Age-attuned care involves comprehensive, sensitive assessment processes responsive to existential distress, spirituality, and cultural needs, that recognise grief and loss at end-of-life associated with loss of personhood and age-related mortality (Durie, 2011; Nicholson & Richardson, 2018; Rosa et al., 2022). Age-attuned practice provides continuity of care within holistic whānau-inclusive interventions, compassionate community approaches involving interdisciplinary and community-based collaborations, and multidisciplinary clinical interactions within hospice (Nicholson & Richardson, 2018). Holistic, whānau-inclusive care empowers patient and whānau involvement within decision-making process, such as the prioritisation of family meetings.

### Ageist discourse

Negative societal attitudes and ageist discourse, including a low value placed on growing older and ageing, negatively impacts palliative care amongst service providers and older adults (Gott et al., 2011). To reduce age-related inequity, gerontologists and palliative care researchers recommend better access to specialist palliative care, including geriatric nursing, primary care, and medicine (Gott et al., 2011; Rodríguez-Prat et al., 2017; Rosa et al., 2022). Ageism and care-provision discrimination observed within practice includes the expectation that older adults will access ARC if prolonged inpatient care is required. Accessing ARC can have long-term detrimental economic, social, and psychological impacts for older adults struggling with the implications of a recent or long-term adverse diagnosis. Furthermore, ARC admission expectations are less likely to occur for younger palliative patients.

Publications containing ageist discourse perpetuate negative self-perception and discrimination experienced by older adults, particularly when they focus on increased

fragility and comorbidities that problematise longevity and the process of growing older (Gott et al., 2017; Miller et al., 2017; Morgan et al., 2021). Literature celebrating older adults' agency and ability to respond to threats to their well-being are often marginalised within media coverage (Morgan et al., 2021). Evidence of ageist discourse related to international epidemiological data that highlights older adults' susceptibility to the virus can be found within Covid-19 pandemic literature and media items (Ministry of Health [MoH], 2020; Morgan et al., 2021). This includes coverage that prioritises economic impacts over protecting the safety and health of older adults that perpetuate the ideology older adults are less worthy of social investment (Flett., 2020; Gott et al., 2017; Morgan et al., 2019; Morgan et al., 2021). Systems theories connect devaluing a population group and marginalisation within public policy to discrimination experienced by older adults during the Covid-19 pandemic (Morgan et al., 2021; Payne, 2014).

Morgan et al.'s (2021) study of Aotearoa New Zealand media during March 2020 identifies significant age-related discrimination. Ageist discourse within the media articles *others* older adults by referring to them to as a homogeneous group of nameless, passive, at-risk members of society (Flett, 2020; Morgan et al., 2019; Morgan et al., 2021; Wiles & Jayasinha, 2013). Media coverage stigmatising older adults as inherently vulnerable and passive, as opposed to situationally at risk, disregards diversity within the older population, particularly social contexts, and intersectional implications, including ethnicity (Pihama & Lipsham., 2020; Morgan et al., 2021). Documentation and media items describing older adults as frail and passive, including publications that connect care goals to cost incurred with an emphasis on cost-saving strategies, devalues their contribution to society (Cheyne et al., 2011; Gott et al., 2017; Morgan et al., 2021).

### National and international strategic planning

Palliative care strategy plans are required to acknowledge and meet the needs of older adults as the numbers of deaths within the oldest age groups are rapidly rising in most developed countries (Castelli Dransart et al., 2021; Gott & Ingleton, 2011). A lack of understanding of older adults' end-of-life preferences globally, including Indigenous older adults and Māori, marginalises their voices within palliative care strategy plans nationally and internationally.

The MoH Review of Adult Palliative Care Services in New Zealand (2017) acknowledged the specific palliative needs and aspirations of older adults and recommended clear funding and service access pathways to empower equitable outcomes. This review reflects palliative care policies across developing countries that prioritise providing opportunities to experience a good death whilst minimising the perspectives of older adults (Castelli Dransart et al., 2021; Gott et al., 2017). This has relevance for those of advanced age, defined with gerontology literature as people aged 85 years and older, who are understood to experience the highest levels of marginalisation amongst older adults within palliative care (Gott et al., 2017; Smith et al., 2002).

Current strategy documents discussing the palliative care needs and aspirations of older adults do not reflect the voices and perspectives of this community (Castelli Dransart et al., 2021). The Aotearoa New Zealand MoH (2001) Palliative Care strategy acknowledges that most people requiring palliative care are older adults and maintains everyone should have equitable access to support services conversant with individual end-of-life preferences. However, there are no clear funding or resource allocation guidelines to support these goals, while detailed guidelines for older adults are deferred, awaiting higher-level policy decisions. Systems theory perspectives

connects older adults' capacity to access quality palliative care to a lack of robust policy, funding and resource allocation—this includes inadequately funded in-home support that reduces an older adult's ability to stay at home (Payne, 2014). Furthermore, the Palliative Care Strategy (MoH, 2001) strategy is over 20 years old, indicating a review is required to meet current palliative care needs.

Negative self-perception impacts older adults' sense of self-worth within family, whānau relationships, including experiencing whanaungatanga (reciprocity) and receiving care from family members. This is reflected within Te Puawaitangi O Nga Tapuwae Kia Ora Tonu, Life and Living in Advanced Age (LiLACs NZ) study results that show Māori and non-Māori participants identify "not being a burden to my family" as their main end-of-life priority (Gott et al., 2017). Experiencing a home death is not within the top three end-of-life preferences chosen by study participants (Gott et al., 2017). This is oppositional to the Palliative Care Strategy (MoH, 2001) that outlines a commitment to supporting home death, and states 50–70% of people prefer home-based care. The Gott et al. (2017) study results challenge national and international palliative care policy development that maintains home death is essential to a good death.

Perceptions of being a burden receive limited attention within research, policy development or strategic planning (Castelli Dransart et al., 2021; Gott et al., 2017). Age-attuned policy development challenges perceptions of being a burden by recognising the significant contributions older adults have made throughout their lifetime to society, and within whānau relationships (Gott et al., 2017; Nicholson & Richardson, 2018). Challenging perceptions of being a burden is a significant social issue as assisted dying research indicates this perception can be an underlying factor for requesting euthanasia (Castelli Dransart et al., 2021; Coyle & Sculco, 2004; Kelly et al., 2002; Rodríguez-Prat et al., 2017).

## Covid-19 pandemic implications

Older adults in ARC endured palliative care inequity prior to the Covid-19 pandemic; this inequity continues to be a serious healthcare concern nationally and internationally (Gilissen et al., 2020; Pivodic et al., 2018). Palliative approaches such as holistic assessments, referrals to palliative care specialists, symptom management and familial support are minimised within international, ARC strategy documentation (Ferrell et al., 2018; Gilissen et al., 2020). Whilst Covid-19 mortality disproportionately affects older adults in ARC globally, international responses to the pandemic focus on infection control and prevention with limited acknowledgment of older adults' palliative care (Ferrell et al., 2018; Gilissen et al., 2020; Pivodic et al., 2018). This includes the World Health Organisation (2020) "Preventing and managing COVID-19 across long-term care services" policy brief which gives limited attention to prioritising older adults' palliative care.

International ARC strategies inadequately address non-physical symptoms, including older adults' social, psychosocial, and spiritual needs, with dementia barely acknowledged. This is a notable omission, as many ARC facilities care for older adults experiencing dementia (Honinx et al., 2019; Wang et al., 2020). "Advanced Care Planning" and recording the end-of-life preferences of older adults is incorporated within international COVID-19 strategies. However, there is an emphasis on recording "do not resuscitate" information, with limited attention to empowering education and communication skills to achieve holistic, comprehensive advanced care planning for older adults (Gilissen et al., 2020; Rietjens, et al., 2017). Systems theory perspectives connect marginalisation within international Covid-19 guidance strategies to older adults' experiences of inequitable palliative care outcomes within ARC globally.

## Māori perspectives

Māori older adults experience equity deficits within culturally inappropriate, one-size-fits-all palliative care service delivery. Culturally inappropriate services exacerbate inequality by limiting access to resources specific to the unique and diverse needs of whānau (family), hapu (clan), and iwi (tribe) (Durie, 2011; Payne, 2014; Roberts, 2016). Durie (2011) maintained inequity is foregrounded by Eurocentric domination culminating in Māori alienation and disempowerment (Durie, 2011; Egan & Maidment, 2016; Roberts, 2016). Māori older adults' inequity experiences are connected to the negative impacts of colonisation affecting Indigenous populations worldwide; this includes higher mortality rates and well-being deficits that are attributed to societal marginalisation, land loss, and cultural disenfranchisement (Zambas & Wright, 2016). Empowering access to culturally appropriate palliative care for older Māori adults involves reconnecting Māori to cultural heritage—that is their birthright. This can be achieved through policy development that empowers tino rangatiratanga (self-determination), and addresses grief, loss and trauma experienced across the lifespan (Pihama et al., 2017; Pihama et al., 2020; Roberts, 2016).

Te Tiriti o Waitangi (1840), negotiated between the British Crown and Indigenous Māori, is foundational to Aotearoa New Zealand public policy (Durie, 2011; Egan & Maidment, 2016; Kidd et al., 2021; Roberts, 2016). To uphold Te Tiriti o Waitangi, the Aotearoa New Zealand government health policy needs to protect and promote the well-being of all Māori (Kidd et al., 2021). The right to express tino rangatiratanga is considered pivotal to empowering Māori rights within Aotearoa New Zealand primary health, and palliative care services (Durie, 2011; Egan & Maidment, 2016; Kidd et al., 2021; Roberts, 2016). Equality for Māori within Te Tiriti is empowered within three articles encompassing concepts of sovereignty, land, and rights. Sovereignty is particularly

relevant, and systems theory perspectives recognise ongoing well-being inequities are perpetuated within government systems that do not empower Māori sovereignty over all things Māori. Boulton et al. (2020) maintained equality and meaningful biculturalism between Aotearoa New Zealand Treaty partners will only be realised when authentic power-sharing is achieved at a structural level.

Aotearoa New Zealand social work practitioners are committed to empowering biculturalism and ensuring palliative care practice approaches respond to Mātauranga Māori knowledge systems, perspectives, and worldviews (ANZASW, 2019). Aotearoa New Zealand palliative care practitioners are encouraged to engage with Mauri Mate, a Māori Palliative Care Framework for Hospices (Totara Hospice et al., 2020). Mauri Mate provides compassionate, culturally appropriate guidelines to improve end-of-life care outcomes for patients, family and whānau, including culturally responsive grief and loss support.

Te Māoritanga perspectives empower holistic, harmonious well-being practices that acknowledge the importance of considering person and family, and whānau well-being within palliative care. For example, Aotearoa New Zealand palliative care assessments often utilise Te Whare Tapa Wha holistic well-being ideologies of achieving *balance* within a *whare* conceptualised as interlinked dimensions representing physical, spiritual, mental/emotional, and family, whānau/family well-being or, “four walls of a house” connected to a place of belonging, or whenua/land (Durie, 2011; Roberts, 2016). Pākehā are encouraged to seek Kaiāwhina cultural support and guidance when engaging with Indigenous concepts and Māori patients (Durie, 2011; Roberts, 2016; Totara Hospice et al., 2020). Empowering Māori equity of access to palliative care includes access to rongoā Māori, or traditional healing systems (Durie, 2011).

Access to Māori specific trauma-informed palliative care for older adults is an important equity issue. According to Pihama et al. (2020), trauma-informed care within Aotearoa New Zealand lacks culturally appropriate responses. Māori behavioural health experts and researchers concur, stating Māori experience collective trauma, including loss and grief connected to disadvantage and marginalisation, as well as intergenerational and historical trauma requires Māori-specific, trauma-informed care (Durie, 2011; Pihama et al., 2017; Pihama et al., 2020; Roberts, 2016). Pihama et al. (2020) encouraged practitioners to engage with “by Māori, for Māori” knowledge and resources responding to Māori-specific trauma, including education for palliative and healthcare professionals, access to culturally appropriate psychosocial supports responsive to Māori specific needs and aspirations, and encouraging earlier referrals to specialist supports, to enhance equitable outcomes for older Māori adults.

### LGBTQ+ experiences

LGBTQ+ older adults, including, but not exclusive to, lesbian, gay, bisexual, transgender, queer, and intersex older adults, are understood to experience increased concern for their safety and well-being, including discrimination and social isolation, within end-of-life care (Cartwright et al., 2012; Kortés-Miller et al., 2018). Inequitable access to palliative care for LGBTQ+ older adults is connected to marginalisation within research, legislation, and policy development (Fenaughty & Pega, 2016; Kemery, 2021; Kortés-Miller et al., 2018). Systems theories recognise marginalisation within legislative processes leads to older LGBTQ+ adults experiencing inequity of access to palliative care (Fenaughty & Pega, 2016; Payne, 2014).

Legislation has played a pivotal role in determining how personhood and human rights of non-heteronormative population groups are understood. Within Aotearoa New Zealand, same-sex intercourse between

men was criminalised following the adoption of British law, formalised by the signing of Te Tiriti o Waitangi (1840). The Homosexual Law Reform Act (1986) decriminalised homosexuality, however; this legislation cannot achieve equality if other social structures and policies do not empower anti-discriminatory practice (Fenaughty & Pega, 2016). Anti-discrimination statutory measures within Aotearoa New Zealand empowering LGBTQ+ human rights, includes the Human Rights Act (1993). Within the Human Rights Act (1993) discrimination towards “self-identities” including age, ability, colour, religious beliefs, and race is prohibited. However, the Human Rights Act (1993) does not explicitly identify or provide protection for LGBTQ+ sexual and gender diversity. Fenaughty and Pega (2016) stated policy development deficits foregrounding gender and sexual diversity inequity, and a lack of research exploring their specific social and well-being needs can be attributed to the Human Rights Act (1993) not specifically identifying this population. Neglecting to specifically identify LGBTQ+ inclusion detrimentally impacts their equitable access to quality palliative care.

To reduce inequity of access to palliative care, service providers are encouraged to provide clear indications that their services welcome LGBTQ+ patients, family and whānau; this includes ensuring websites and admission information explicitly states gender expression, sexual orientation, and gender identity inclusivity are embraced (Bristowe et al., 2018; Maingi et al., 2018). Palliative care inequity of access is perpetuated when there is minimal information, research and literature examining palliative care experiences of LGBTQ+ older adults, including comparisons between LGBTQ+ older adults and the experiences of non-LGBTQ+ service users (Stinchcombe et al., 2017). Research related to older LGBTQ+ adults palliative care equity issues often focuses on individuals’ fears surrounding future care

needs, while disregarding the perceptions and experiences of the care received (Haviland et al., 2021).

Research examining LGBTQ+ health care issues and concerns recommends palliative care providers demonstrates a commitment to ensuring palliative care practitioners and clinicians have the knowledge and skills to meet the needs of LGBTQ+ older adults (Kemery, 2021). Practitioners providing direct care, including social workers, nurses, and physicians, are encouraged to undertake additional education related to LGBTQ+ specific trauma, including the effects of discrimination across the lifespan on a person’s health and well-being (Maingi et al., 2018).

Trauma experienced across the lifespan is particularly relevant within ARC contexts. Research shows gender and diverse sexuality minorities expect to access ARC as they age and receive end-of-life care within these settings (Furlotte et al., 2016). Amongst LGBTQ+ older adults entering ARC facilities there is an expectation that they will encounter stigmatisation and discrimination within unsafe social and physical environments, and experience loss of independence and loss of identity (Furlotte et al., 2016; Kortess-Miller et al., 2018). Older adults commonly express fear and loss of quality of life as a concern when accessing ARC. However, older LGBTQ+ adults’ inequitable experiences are often compounded by the “loss of identity statuses,” as diverse identities may not be recognised within ARC, this includes access to specialist care support unique to maintaining diverse identity statuses (Furlotte et al., 2016; Kortess-Miller et al., 2018).

### Caregivers, family and whānau

Inequity of access to palliative care detrimentally affects the caregivers of older adults. Internationally, palliative care services continue to be underutilised by



older adults, family and whānau caregivers despite an increased need for palliative care for older adults (Ahmed et al., 2004). This is significant as family caregivers are estimated to provide 75–90% of home-based end-of-life care (Dunbrack, 2005). Many studies documenting home-based palliative care acknowledge caregivers' distress, including depression, anxiety, social-isolation, deterioration of family relationships and fatigue (Belasco et al., 2006; Schoenmakers et al., 2010; Wong et al., 2022). Wong et al.'s (2022) research examining caregiver experiences of elderly patients end-of-life care illuminates the detrimental impacts of caregiver inequity of access to palliative education and knowledge, including information explaining health status and service provision. Access to palliative care information and knowledge has been shown to reduce caregiver distress and increase positive end-of-life experiences amongst families of older adults (Wong et al., 2022; Yang et al., 2012).

Inequity experienced by caregivers of older adults includes access to income support and social services while providing unpaid care. Informal caregivers incur significant indirect and direct costs when providing unpaid end-of-life care for older adults, which can result in incurring debt and bankruptcy (Egan & Maidment, 2016; Gott et al., 2015). Gott et al. (2015) maintained that the cost to family and informal caregivers is minimised within research and policy that emphasises the cost to society. This inequity disproportionately impacts Māori caregivers as they are affected by higher levels of costs and unmet primary care generally, this includes Māori socioeconomic marginalisation which increases their cumulative financial burden (Cheyne et al., 2011; Durie, 2011; Gott et al., 2015; Roberts, 2016). Marginalisation and inequity amongst caregivers of older adults is also evident within strategic planning documentation that prioritises reducing societal costs and minimises acknowledging the cost to patients and families (Castelli Dransart et al., 2021; Gott et al., 2017; MoH, 2001).

Gott et al. (2015) maintained that research and policy development quantifying and responding to the financial costs incurred by families is required as developing countries move towards community-based palliative care provision. Systems theories perspectives acknowledge the role and pressures experienced by family and whānau caregivers, including caregivers' personal, financial, and social costs, by connecting family distress to policy deficits (Egan & Maidment, 2016; Gott et al., 2015; Payne, 2014). Systems theory critical analysis connects "family is best" to "family is cheapest" ideologies that are conversant with Aotearoa New Zealand's third-way political system that prioritises reducing the cost of palliative care to the state (Cheyne et al., 2011; Gott et al., 2015; Payne, 2014). Inequity of access to palliative care amongst older adults is exacerbated for those living alone or socially isolated without the social networks required to bridge gaps within service delivery by providing unpaid, home-based care (Cheyne et al., 2011; Gott et al., 2015; Payne, 2014).

Studies show that, despite the movement towards community-based palliative care, and subsequent home-based caregiving, many palliative patients frequently require hospitalisation at the end of life across developing countries (Robinson et al., 2014). Frey et al.'s (2020) research examined caregiver satisfaction within palliative care services and found caregivers experienced higher levels of satisfaction with hospice care, and the lowest within hospital-based end-of-life care. Systems theories connect family and family, whānau caregiver inequity of access to older adults' inequitable palliative care experiences as these issues are interrelated, including end-of-life hospitalisation as this strongly indicates resourcing, and specialist assistance for family and whānau is inadequate (Frey et al., 2020; Payne, 2014).

## Conclusion

Older adults would benefit substantially from access to palliative care across their illness trajectory, yet they continue to be the *disadvantaged dying* within end-of-life services. Research identifies inequitable outcomes for older adults is exacerbated within marginalised communities, including LGBTQ+ and indigenous populations, and by unpaid caregivers providing home-based care.

Systems theories and social work perspectives were utilised to examine older adults' inequitable access to palliative care and explore the intersections between pervasive ageist discourse within society, national and international policy development, strategic planning documentation, and the marginalisation of older adults' voices, perspectives and aspirations within research and service delivery.

Gerontological research advocates for age-attuned policy development and specialist education for palliative practitioners as the way to effectively disrupt age-related inequity and improve outcomes for older adults within palliative care services.

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