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## **Title Page**

**Title:** Gender and Family Caregiving at the End-of-Life in the Context of Old Age: A Systematic Review

**Authors:** Tessa Morgan BA, Lisa Ann Williams PhD, Gabriella Trussardi PhD, Merryn Gott PhD

**Institutional Affiliation:** School of Nursing, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, New Zealand.

**Each author's current appointment and work address:**

Tessa Morgan: Research Assistant, School of Nursing, The University of Auckland

Lisa Ann Williams: Research Fellow, School of Nursing, The University of Auckland

Gabriella Trussardi: Research Assistant, School of Nursing, The University of Auckland

Merryn Gott: Professor of Health Sciences, School of Nursing, The University of Auckland

**Address:**

School of Nursing

Faculty of Medical and Health Sciences

The University of Auckland

Private Bag 92019

Auckland, New Zealand

**Contact details of corresponding author:**

Tessa Morgan

School of Nursing

Faculty of Medical and Health Sciences

The University of Auckland

Private Bag 92019

Auckland, New Zealand

E-mail: [t.morgan@auckland.ac.nz](mailto:t.morgan@auckland.ac.nz)

## **Abstract**

**Background:** As societies age and governments attempt to manage within constrained health budgets by moving care into community settings, women will be called upon to provide more palliative care in old age. However, little is known about gendered disparities for carers of people over the age of 65.

**Aim:** To identify and synthesise the empirical literature between 1994-2014 that focuses on gender and family caregiving for people over 65 with a life limiting illness.

**Design:** Systematic review of qualitative and quantitative studies conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Supplemental review using a novel feminist quality appraisal framework.

**Data sources:** Search of MEDLINE, Cinahl, PsycINFO, Sociological Abstracts and Gender Studies to find empirical studies on gender and family caregiving at end-of-life in the context of old age.

**Results:** Of 19 studies identified, 9 presented thorough gender analyses. Gender themes included why people care, how they care, and the consequences of providing care. Women carers experienced a greater degree of mental and physical strain than their male counterparts. This was linked to societal expectation that women should provide a greater degree of care at the end-of-life for family members.

**Conclusions:** Palliative family caregiving for older adults is gendered. Gender affects why people care and the consequences of providing care. Palliative care literature needs to incorporate a greater gender focus for future research and policy-makers need to be aware of the gendered ramifications of providing more palliative care in the community.

## **Keywords**

Palliative care, end-of-life care, family caregiving, informal care, gender, older adults

## **What is already known about the topic?**

- To date, palliative care research in the context of old age has rarely considered the gendered impact of such care despite the wide acknowledgement that women provide the majority of family caregiving at end of life.
- Women all over the world will have to shoulder significantly more caregiving burden as a direct result of their governments' attempts to push palliative care into the community.
- Providing care to a family member affects women's mental and physical health more negatively than it does men.

## **What this paper adds?**

- Evidence that gender significantly impacts the provision of palliative care by family members both in terms of the reasons to provide care and the outcomes of providing care.
- The review identified 19 studies relating to gender and family caregiving in the context of palliative care; 9 presented thorough gender analyses.
- Our novel feminist quality appraisal framework highlighted a significant variance in the nature of gender analyses used.

## **Implications for practice, theory or policy**

- Further research is required to explore the complex construction of gender and family caregiving in the end-of-life context which is currently limited.
- This review has outlined the importance of health professionals developing gender sensitive strategies to assist family caregivers at this time of intense need.
- Policy-makers all over the world need to be aware of the gendered ramifications of expanding more palliative care into the community and how this will disproportionately affect women.

## **Background**

Older women comprise a significant proportion of the world's population, and this trend is only predicted to increase.<sup>1</sup> The United Nations has reported that the number of women aged 60 and over will increase from about 336 million in 2000 to just over 1 billion in 2050.<sup>2</sup> By 2050 there will be “189 women for every 100 men” living over 80 years of age.<sup>2 p. 3</sup> As societies age, there will be a greater demand for palliative care in the context of old age, as well as an ageing pool of family carers.<sup>3</sup> This burden of care will fall disproportionately on women, first spouses, but also daughters and daughters-in-law, who have been traditionally relied on “for management of health, and acute and chronic illness” in the home.<sup>4-7</sup> These societal expectations have real world implications, for even women aged 80 and over provide a significant portion of unpaid family caregiving.<sup>8</sup>

Another factor exacerbating the expectation of women to provide at-home care stems from Western governments’ policy decisions to shift the onus of care away from the often publicly-funded formal care system.<sup>9-12</sup> This re-domestication of care presupposes the contribution of family members – especially women – to make home care possible.<sup>9-13</sup> These responsibilities rest on top of their pre-existing caring role for which they receive none of the recompense guaranteed in public formal work.<sup>10</sup> Moreover, a greater proportion of women will continue to die inside the purview of the formal system, and indeed expect to, because they are less likely to receive informal care themselves due both to their reluctance to be a burden on their family members and in part because they tend to outlive their spouses if in heterosexual relationships.<sup>14, 15</sup>

Furthermore, the existing literature on family caregiving shows that the experience negatively affects women more than men. Women are at a greater risk of stress, anxiety and depression than men who provide care and non-carers, as well as self-reporting more unmet psychosocial needs as a result of providing higher and more intense levels of care.<sup>3, 16</sup> Women carers also report lower levels of subjective well-being and physical health and often suffer from higher

rates of physical and/or psychological co-occurring ailments than men.<sup>2, 17, 18</sup> Compounding this, women providing family caregiving are more likely to live in poverty.<sup>2, 8, 18</sup>

Taken together, these factors indicate a significant gender inequality at the heart of palliative care. As such, a systematic review of how gender is attended to in the palliative care literature, especially in light of the fact that older female spouses are increasingly responsible for their partners' care at a time of intense need, seems overdue.<sup>18</sup> To our knowledge, no systematic review has been conducted that considers the use of gender in informal palliative care in the context of old age; therefore it is our aim to do so by looking at the palliative care literature from the last 20 years. Informed by our own feminist commitment to the equal treatment of all genders, we have employed a feminist analysis to assess the literature. We understand a feminist analysis to be centred on questions about the construction of power and gender in any given society as well as a commitment to discover ways to improve women's position in society.<sup>19</sup> In particular, such an analysis will help highlight the gendered power relations that underpin the uneven outcomes implicit in the provision of care.

### **Aim**

1. To identify and synthesise the empirical literature from the past 20 years that examines the relationship between gender and family caregiving at end-of-life of patients over 65 in order to explore how gender as a social construction impacts on carers' experiences.

### **Methods**

For the purpose of this review 'family caregiving' will be understood as care provided at home by an "informal carer" who is a "family member, friend, or fictive kin who provides some form of care to an older adult with whom they have a relationship".<sup>20 p. 1008</sup> Gender is to be understood as "the social, cultural and symbolic construction of femininity and masculinity in any given society".<sup>19 p.242</sup> Moreover, our focus is on palliative care in the context of old age and as such, the inclusion criteria specified that care recipients must be over the age of 65.

### **Data Search**

We searched five electronic databases (MEDLINE, Cinahl, PsycINFO, Sociological Abstracts and Gender Studies) for articles published in the last 20 years (Jan 1994 to Nov 2014) using a search strategy devised in collaboration with a specialist subject librarian. Search terms were developed in relation to our key search areas and were subsequently refined and in certain

cases expanded following a preliminary search (Figure 1). Notably, we decided to exclude ‘female’ and ‘male’ from the search terms because the usage was focused specifically on the biological sex rather than gender, and inflated the search unnecessarily. The final criteria comprised peer-reviewed, English-language articles on palliative care in the context of old age (over 65) and informal care with a prime focus on gender (Table 1).

Over a period from November 17<sup>th</sup> 2014 to December 22<sup>nd</sup> 2015 Tessa Morgan (TM) independently screened titles and abstracts of all articles to identify those which met the study’s inclusion criteria. All articles that passed into the abstract stage were compared against a data extraction template – a modified version of Hawker et al. – providing a short-hand reference to the inclusion criteria.<sup>21</sup> Those that the first reviewer was unsure about were subsequently reviewed by Lisa Williams (LW). The articles included from the abstract stage were then read in full and their reference lists searched. Articles found in this way were also included if they met the criteria. The articles from this stage that remained indeterminate were also reviewed by Merryn Gott (MG) in consultation with TM and LW.

### **Data analysis**

As the studies incorporated in this review contained methodologies representing different paradigms, we employed a descriptive thematic analysis to review and synthesise the research. This method allowed for a structured way to identify themes across different literature, while ensuring flexibility to develop themes in a data-driven manner.<sup>22, 23</sup> We could not find a suitable quality appraisal tool that would appraise gender and therefore we derived our own feminist quality appraisal framework which we subsequently compared our included articles against (Table 2). The purpose of the framework was to assess the rigour of the gendered analysis employed in the articles included in the review. The framework assessed how gender was used in data collection (participants responses); data analysis (gender used as socially constructed category); and discussion (societal expectations, intersecting disparities and effective ways forward). TM judged whether studies should be considered thorough, moderate or cursory, in relation to the degree to which each study fit the five criteria included the framework. TM then consulted with LW and MG until consensus was reached as to the feminist quality of each study.

### **Results**

Search results are summarised in the adapted Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Figure 2). A total of 13 studies met our inclusion criteria from our database search with a further six included from the hand-search process. Of these 19 studies, seven were quantitative, seven were qualitative, one was a literature review, and four used mixed methods. The quality of the gendered analysis varied greatly, with nine studies (seven qualitative, one quantitative and one mixed methods) presenting a thorough feminist analysis, according to our framework. Simply having gender as a main focus did not ensure that the gendered nature of disparate power relations and their effects were taken into account. By the same token, a gender focus did not equate to a feminist account which requires a greater focus on achieving gender equality within the methods of the study and outcomes of research. Three key themes were identified pertaining to gender and will be discussed in the following section: why people care, how they care, and the consequences of providing care.

### **Why women and men care**

Feelings of responsibility and reciprocity for family members were repeatedly cited in the literature as the underpinning motivation for providing care.<sup>24-27</sup> Nevertheless, the literature indicated that this duty fell considerably more on women than men in the Western context, with the popular idea of a ‘dutiful’ daughter or ‘nurturing’ wife having a palpable effect on the provision of care.<sup>4</sup> This difference is apparent where women in general expect to live out their deep old age in formal care and increasingly do, even as men continue to expect to be cared for by their spouses.<sup>9</sup> Female longevity certainly affects these assessments, but they are also evidently influenced by normative ideas of gender roles.<sup>9, 28-30</sup> Other interceding factors include the marital status of the carer, for as Campbell found, never-married sons provided more care than married sons.<sup>26</sup> Nonetheless, Campbell is sceptical of ‘externalist’ reasons, put simply, that patriarchy can explain why caregivers are predominantly female, because she believes this ascribes a false passivity to the actors involved in day-to-day caring.<sup>26</sup> The importance of context is particularly apparent when looking at the non-Western setting of Tibet and China. Two studies focusing respectively on these countries demonstrated how expectations of care fell on the eldest son and his wife, whereas married daughters were expected to provide no care for their birth families.<sup>31, 32</sup> Differences in the construction of gender across countries and cultures reinforced the power of normative ideals of gender on how people conducted themselves and explained their actions and behaviour.<sup>24</sup>

## **The performance of care**

Gendered expectations shaped the nature of care provided. All studies showed that women were more likely to be carers than men. Where men did identify as carers, on average, they provided less time caring than women.<sup>9, 33</sup> These studies also revealed that women and men tended to provide different types of care. Whereas men were more likely to provide instrumental support such as mobility-related tasks, women were twice as likely to provide assistance in toiletry-related tasks and other more intimate aspects of personal care.<sup>9, 28, 34</sup> Two studies found that women provided more intensive instrumental care that involved more heavy lifting than men.<sup>34, 35</sup> Linked to this was the way in which women and men perceived their caring roles differently. Husbands providing palliative care often saw their role in terms of a job, applying a managerial order to their caring, while wives tended to see themselves more as nurturers.<sup>36</sup> As a consequence, women were less inclined than men to rely on formal care services when providing care for a family member, which authors linked with women's expectations of taking on a higher level of care.<sup>28</sup> Nevertheless, other studies revealed that not all carers' experiences fit into this neat dichotomy, as in reality there was a significant blurring between traditionally ascribed roles.<sup>24, 26, 36</sup> Within this intricate web of identities, not everyone accepted the identity of carer, opting to see themselves as fulfilling their duties as a spouse.<sup>24</sup>

Other studies explored how palliative care intersected with additional significant caring roles. At the same time as undertaking palliative caring women fulfilled other caring roles, for example, as mothers, spouses and friends.<sup>4, 28, 34, 37</sup> Unsurprisingly, women struggled when caregiving conflicted with competing demands.<sup>4, 38</sup> Compounding such demands, women – especially in the case of daughters – felt adversely affected when the care expected from them was unequal to that of their brothers.<sup>4</sup> Furthermore, caring for a parent at the end of life had repercussions on carers' other relationships. Sutor and Pillemer found that husbands of women caring for their parents sometimes withheld emotional support when they perceived their wives were neglecting them.<sup>39</sup>

## **Physical and mental health of the carer**

Gender was most prominently discussed in relation to the different experiences of carers of mental and physical health impacts. First, with regard to mental health, all studies found that female carers faced a greater incidence of mental strain than both male carers and non-carers.<sup>33, 38, 40</sup> One study found that women suppressed their emotions to “maintain a pleasant and perceived socially acceptable disposition”.<sup>30 p. 821</sup> Mental strain was also linked to depression,



which women suffered disproportionately.<sup>28</sup> Two studies argued that these negative mental health impacts were not shared equally between all women, but rather that in terms of self-esteem wives are far more vulnerable than daughters.<sup>33, 38</sup> Other scholars, who focused on men as carers, asserted that men also experienced negative emotions as a result of caregiving, but had a tendency to suppress their emotions, which resulted in the literature misrepresenting their experiences.<sup>24, 26, 29, 35, 41</sup> Moreover, some authors identified gender as just one factor mediating the impact on caring as the health of the care recipient and financial security also contributed.<sup>37, 41</sup>

A gender variation was also evident in physical health of carers. A significant proportion of the literature reported that women sacrificed their own health care issues in order to provide care for their spouse which resulted in the exacerbation of their co-morbidities during the care process.<sup>30</sup> This is important when it is appreciated that informal palliative carers are most likely to be women spouses, and that women are more likely to suffer from co-morbidities than men.<sup>30</sup> Nevertheless, the literature also emphasised that there were positive aspects stemming from the palliative care experience, including personal development and the satisfaction of providing a ‘good’ death for one’s family member.<sup>26, 33, 41</sup>

## **Discussion**

This is the first review to systematically collate and synthesise the international empirical literature relating to gender and family caregiving at end of life of patients over 65. Adding to its significance is the timely nature of this research. Increasingly the relevance of gender to health in old age is being investigated, as evidenced in the social and feminist gerontology literature.<sup>42</sup> Moreover the way gender affects health is also on the rise as a topic of discussion in the popular press.<sup>43</sup>

This review has highlighted several significant implications for future research. First, the literature has revealed just how important gender is to the experience of end-of-life caregiving across a range of subjects: why people accept the role, the nature of the care they provide, and the health-related outcomes for carers. Indeed, if we are to understand palliative care as “an approach that improves the quality of life of patients *and* their families”, at a time of intense need, then gender must be included as a category of analysis when conducting further research in this area.<sup>44</sup> Two recommendations arising from this review therefore are: the need to apply a thorough gender analysis to new original research in palliative care and the need for further research that reveals the degree to which gender intersects with other identity-defining

characteristics, especially ethnicity, which we have tentatively identified as important to influencing the gendered provision of palliative care.

Additionally, this review has demonstrated the importance of understanding gender as a part of a body of normative ideas that exist within specific contexts. Studies within this review – especially those that met the standards of the feminist quality appraisal tool – focused on how ideas of gender materialised within the particular context they studied, delineated largely by national boundaries.<sup>27, 29-31, 37</sup> A few studies also looked at how ideas of gender change over generations and between ethnic groups within particular societies, which indicates that constructions of gender are neither static nor universal.<sup>24, 27, 30, 32, 36</sup> In line with this approach, we argue that future research should take into account that gender is a malleable product of particular socio-cultural contexts and influenced heavily by the distribution of power within societies. The best way to enable this process is to situate caregiving in the paradigm of femininity, not simply as a commonplace women's role, which surprisingly only two studies in this review did and only in relation to their masculine subjects.<sup>29, 36</sup> Furthermore, other identity-shaping factors, such as age, ethnicity and class, which can modify normative conceptions of gender, could also be assessed in greater depth.<sup>33</sup>

Moreover, when conducting this search we found two reoccurring issues in the literature concerning the usage of gender. First, there was a tendency for studies to conflate discussions of sex with gender, which Calasanti suggested was a wider problem in the biomedical literature often stemming from confusion around the distinction of the two.<sup>29</sup> We posit that conflating the two concepts is particularly important to avoid when researching family caregiving as this confusion reinforces notions of the naturalness of women caregiving, which is itself a social construction. Second, we found that researchers often conflated gender with women and thus never explicitly discussed gender despite its relevance to their studies. At the other end of the scale, one study held that gender was only relevant when viewed comparatively between men and women.<sup>28</sup> As our systematic review reveals, however, there is a growing number of exploratory studies on men as carers which effectively employ gender analyses to interrogate different performances of masculinity without needing to include women in their studies.<sup>29, 36, 41</sup> Therefore further studies should embrace the flexible nature of gender analyses and avoid falling back on outdated assumptions of gender research.<sup>42</sup>

In practice the assumptions underpinning expectations for women to provide family caregiving need to be investigated and challenged. This review has shown how caregiving responsibilities

are in the main shouldered by women. Caregiving responsibilities are also overwhelmingly invisible in the public domain due to the widespread perception that they are a family rather than a policy concern.<sup>9, 29</sup> In this way the palliative care process can be seen to reflect dominant cultural expectations which relegate women to the private sphere and devalue their labour – a process which is exacerbated for older adults because of undercurrents of ageism in society.<sup>45</sup> While many women, and indeed some men, take on their caring roles willingly – motivated by their filial duty to their loved one – many carers still have negative experiences providing care. The high incidence of mental and physical strain experienced by family caregivers, particularly older women spousal carers, attests to the negative side of providing palliative care. Moreover, female family caregivers are more likely to have to sustain these negative effects and indeed do, because the moral imperative surrounding family caregiving at end of life falls disproportionately on women; thereby re-inscribing their disadvantage in society. By challenging the ideal of family caregiving as a feminine necessity in the west, and therefore making the choice to be a family caregiver more genuinely autonomous, we may be able to protect the health of family caregivers, as well as to ensure the efficacy of the care provided.

Studies have argued that one way to achieve this moral reconceptualising is to support more men into caring roles. Studies have argued that in doing so we must take into account the ways that men develop caring strategies are rooted in their “sense of selves as men”, as well as valuing their work through the type of praise which they would have received in their employment.<sup>24, 26, 29, 36, 41</sup> Although these suggestions have merit, taking a “Mr. Wonderful” attitude – a term used by Campbell – esteeming men, while not extending such praise to women, reinforces this devaluing of care work and re-inscribes gendered norms framing women as natural carers.<sup>26</sup> Instead, all carers ought to be valued and their roles demystified in order to move toward a situation where women and men feel comfortable to share their experiences and indeed the workload, so as to improve their caregiving experiences.<sup>46</sup>

This review has outlined the importance of health professionals developing gender sensitive strategies. First, health professionals need to be especially aware of the mental health disparities of women and develop appropriate strategies accordingly to promote self-efficacy and provide encouragement for women carers.<sup>4, 28, 34</sup> Professionals should also be mindful of the masculine gender trait that encourages men to withhold emotion and check-in with them about their wants and needs. The second related point pertains to the need for professional training for family members who wish to provide care, as well as the need for in-home help that will enable carers to have time-off for themselves.<sup>9, 34, 38, 47</sup> Combined, these strategies would help dissipate

expectations that women should shoulder most, if not all, caregiving responsibilities.<sup>16, 28</sup> Such strategies also represent direct ways policy-makers can ameliorate the gendered inequalities inherent in positioning palliative care in the community.

## **Limitations**

The feminist appraisal template focused specifically on the quality of gender analysis evident in the research included in the study. Consequently, other issues related to methodological rigour more typically addressed in conventional systematic reviews have not been examined in as great detail. Second, while electronic search, retrieval and review strategies were used, the search is subject to some limitations. Databases were limited to English, and due to a limitation of resources, a search of the ‘grey literature’ was not conducted. As a result, some studies may have been missed.

## **Conclusion**

Gender has wide-reaching effects on the experience of carers looking after a family member who is both in old age and at the end of life. Gender affects why people care, how they care, and the consequences of providing care. Fundamental to these assessments was the way care was commonly perceived as a natural element of femininity, rendering care invisible (and devalued) and yet a cornerstone of the wider health system. In sum, this review highlights the urgent need for more gender analysis to fill this significant gap in palliative care literature. There is also a need to provide gender sensitive support for family caregivers in order to rectify the gender inequalities perpetuated by the palliative care process.

## **Conflict of Interest Statement**

None.

## **Funding**

University of Auckland

## **Supplementary Materials**

Contact corresponding author Tessa Morgan for more information on how to access and use the forthcoming feminist quality appraisal template framework.

Figure 1:

1. Palliative
2. (MH "Terminally Ill Patients" or MH "Terminal Care") or "terminally ill"
3. Terminal ill\*
4. End of life
5. Last year of life
6. Home based
7. (MH "Home Nursing")
8. Informal care\*
9. Lay care\*
10. Informal support\*
11. Personal assistance
12. ("spou\*" OR "famil\*" OR "home") AND ("care\*" OR "support\*" OR "assist\*")
13. (MH "Caregiver Support")
14. Gender
15. Sex
16. Women
17. Men
18. Feminis\*
19. Feminist gerontology
20. Feminine
21. Masculine
22. Gender role\*
23. Gender norm\*
24. "hegemon\*" OR "patriarch\*"
25. "social\* construct\*"
26. (MH "Sex Role") OR "sex role"
27. (MH "Gender Bias") OR "gender bias\*"
28. Ageing
29. Aging
30. Elder\*
31. (MH "Aged") OR "aged"
32. (MH "Death") OR "death"
33. Dying

Palliative terms

Informal care terms

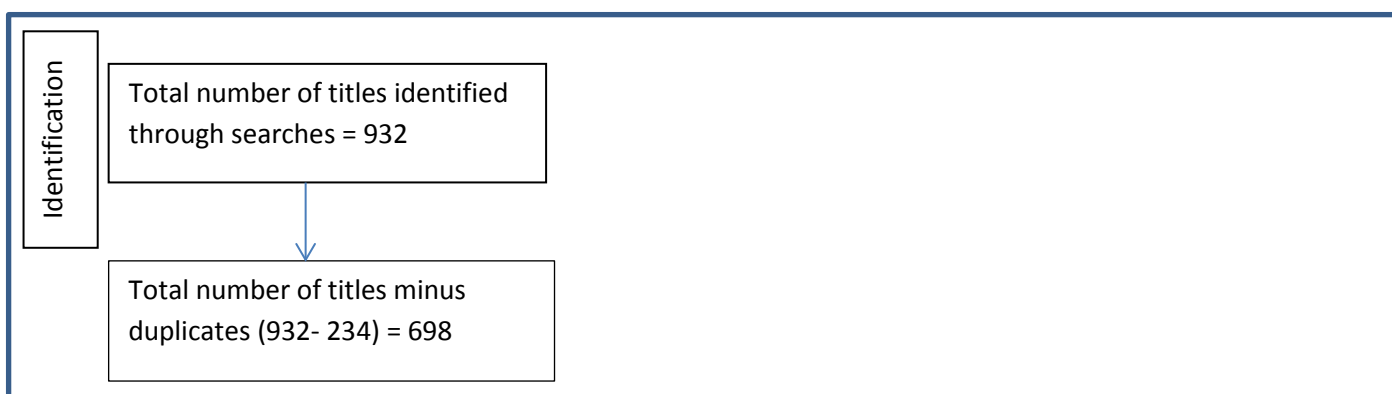
Gender terms

Aging terms

| Inclusion   | Exclusion   |
|---|---|
| Written in English language                       | Written in languages other than English   |
| Articles focusing on gender and family-caregiving | Any study that did not have a key focus on gender, including studies which only referred to biological sex. Studies that focused on caregiving for someone other than a relative. |

|   |  |
|---|--|
| Palliative or end-of-life care provided for someone aged >65 years. | Palliative care in ICU, hospital or hospice and/or by someone who is not a family caregiver. |
| Palliative or end-of-life care in the context of old age (over 65)  | Not focusing on palliative or end-of-life care for a person over 65                          |
| Articles published between January 1994 and November 2014           | Articles before and after this time period   |

Table 1: Inclusion and exclusion criteria for systematic search



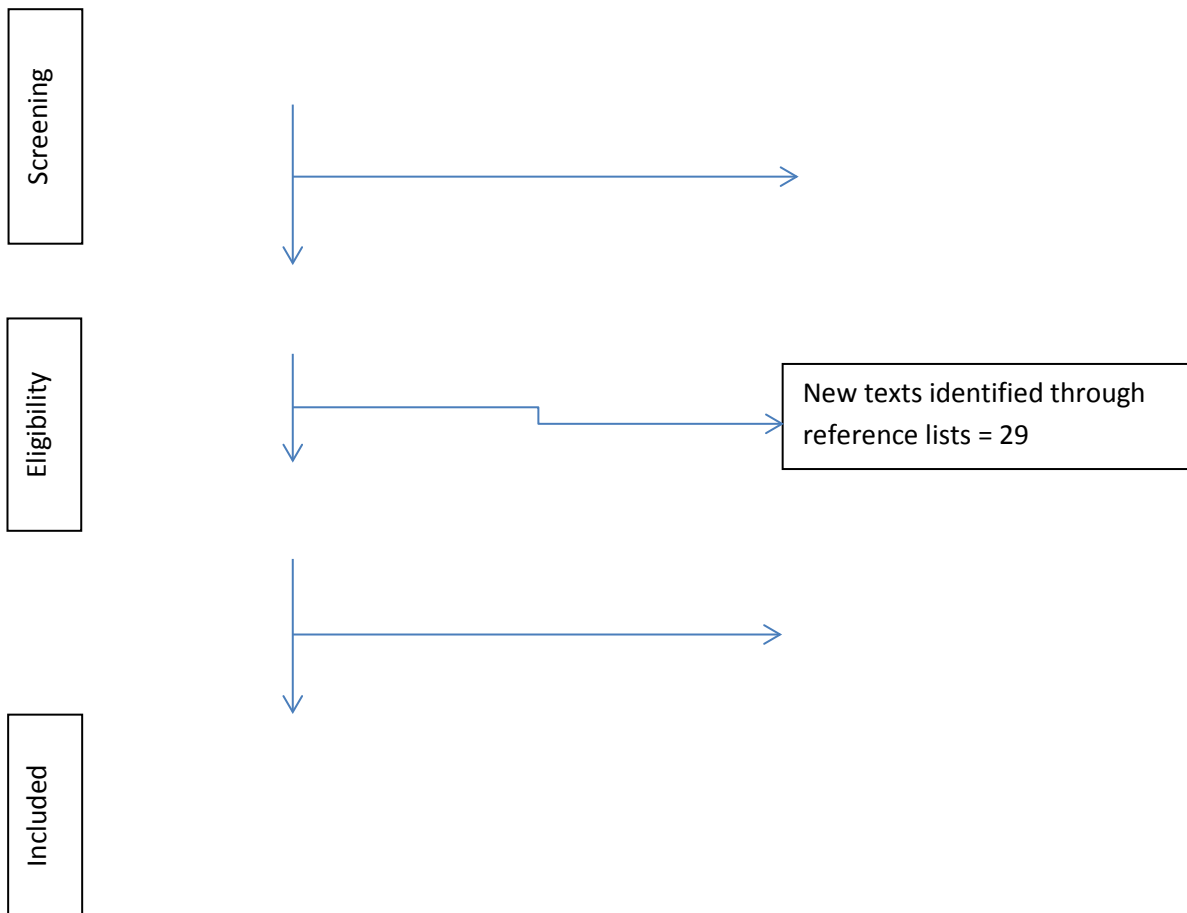


Figure 2. Adapted PRISMA flow diagram of studies  
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

1. World Health Organisation. Women and Health: Today's Evidence, Tomorrow's Agenda. Report. Geneva, 2009.
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