

**Study Title: Barriers to Palliative and Hospice Care Utilization in Older Adults with Cancer: A Systematic Review**

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### **Abstract**

The number of older adults with cancer and the need for palliative care among this population is increasing globally and in the United States. The objective of this systematic review was to synthesize the evidence on the barriers to palliative and hospice care utilization in older adults with cancer. A systematic literature search was conducted using PubMed, CINAHL, PsycINFO, Embase, and Cochrane Library databases (from inception to 2018) in accordance to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Research articles that examined palliative or hospice care utilization in older adults with cancer were included in this review. Fineout-Overholt's Level of Evidence was used for quality appraisal. A total of 19 studies were synthesized in this review. Barriers to palliative and hospice care utilization were categorized into socio-demographic barriers, provider-related barriers, and health insurance-related barriers. Findings revealed that male, racial minority, unmarried individuals, individuals with low socio-economic status or residing in rural areas, and fee-for-service enrollees were less likely to use palliative or hospice care. Lack of communication with care providers is also a barrier of using palliative or hospice care. The factors identified in this review provide guidance on identification of high-risk population and intervention development to facilitate the use of palliative and hospice care in older adults with cancer. Larger prospective studies on this topic are needed to address this critical issue.

***Keywords: older adults; cancer; palliative care; hospice care***

## **Introduction**

Cancer is a global public health problem with 17.0 million new cancer cases diagnosed and 9.5 million cancer deaths occurring worldwide in 2018. With the aging of the population, the global burden of cancer is expected to increase to 27.5 million new cancer cases and 16.3 million cancer death by 2040<sup>1</sup>. In the United States, over 15.5 million individuals with a history of cancer were alive in 2016 and about 1.7 million new cancer cases were expected to be diagnosed in 2018.<sup>2</sup> Older age is one of the most common risk factors for development of cancer.<sup>2</sup> The incidence of cancer is the highest among older adults in the United States. Approximately 60% of cancers in the United States occur in people age 65 and older.<sup>3</sup> Older adults with cancer have high symptom burden and exhibit multiple physical and psychological symptoms including nausea/vomiting, fatigue, loss of appetite, weight loss, altered sleep, musculoskeletal symptoms, neurocognitive symptoms, urinary symptoms, circulatory symptoms, and hormonal symptoms.<sup>4,5</sup> These symptoms significantly affect the quality of life of older adults with cancer.<sup>5</sup> Older adults with cancer also have unique health needs not just associated with the disease itself but also due to bio-psycho-social changes caused due to the aging process as well.<sup>6</sup> Older adults with cancer have high levels of unmet needs including psychological needs, informational needs, and communication needs.<sup>7,8</sup>

Older adults with cancer can benefit from early enrollment in palliative care services. Early utilization of palliative care is associated with symptom relief, improved mood, reduced depressive symptoms, improved quality of life and survival, and overall satisfaction with treatment outcomes.<sup>9-13</sup> Despite the scientific evidence of the benefits associated with palliative care services, there are several barriers to palliative care

utilization in older cancer patients and older adults utilize palliative care services to a lesser extent compared to their younger counterparts.<sup>14,15</sup>

Similarly, older adults with cancer can benefit from hospice care services. Hospice care helps address the multidimensional needs of the patients and families and provides support to patients' family during the illness and following death<sup>16</sup> and is associated with improved quality of life of patients near the end of their lives.<sup>17</sup> Hospice care also improves family functioning provides bereavement support<sup>18</sup> and increases patient satisfaction with care.<sup>19</sup> Enrollment in hospice also reduces overall Medicare costs.<sup>20</sup> However, evidence suggests only half of the patients who die of cancer are ever referred to hospice.<sup>21</sup> In most cases, cancer patients are not referred to hospice until they approach very end of their life with only a few days to live. As a result, the patients and families are unable to fully benefit from the holistic approach to care.<sup>22</sup> One of the primary reasons for the lack of or low enrollment for hospice services is a lack of awareness of the benefits of hospice care. Patients and families are mostly informed about the philosophy of hospice care but are not informed about the practical benefits of hospice care, who provides the care and how it is provided.<sup>23</sup> Moreover, provider's discomfort with end-of-life issues discussions or time constraints in clinical settings were noted as some of the barriers to a timely referral of hospice service.<sup>24</sup>

The rapid growth in the number of older adults with the diagnosis of cancer accentuates the importance of gaining a better understanding of barriers to palliative or hospice care utilization among older adults with cancer. Yet, evidence on the use of palliative and hospice care in older adults with cancer has not been systematically reviewed. Therefore, the goal of this systematic review was to synthesize the scientific

evidence on barriers to utilization of palliative and hospice care among older patients with cancer.

## **Methods**

### **Literature Search and Selection**

Comprehensive literature searches were conducted using the PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, Embase, and Cochrane Library databases. The key words for literature search included (cancer OR neoplasms OR oncology) AND (“palliative care” OR “supportive care” OR "end of life" OR hospice OR terminal OR dying) AND (barriers OR obstacles OR challenges OR difficulties) from inception to June 2018. Articles were limited by age filter of ‘aged 65 and above’ to focus on articles related to older adults. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed for literature search.<sup>25</sup> Ancestry searches was conducted from identified studies and manual search was conducted to retrieve additional research articles.

This systematic review included articles that examined either palliative or hospice care utilization in older adults with cancer. For the purpose of this review, older adults are defined as individuals of age of 65 or older. Articles were included if they met the following inclusion criteria: 1) focused on older adults with cancer, 2) examined the factors associated with palliative or hospice care utilization, 3) published in a peer-reviewed journal, 4) written in English language, and 5) have accessible full text. To be broad and inclusive, for articles that include participants across age groups, articles were included as long as they reported on the older age group. This review only included original research, but no restrictions were placed on research design in order

to maximize all relevant research evidence available on this topic. Quantitative, qualitative or mixed methods studies were deemed eligible for inclusion in this study. Systematic review studies were not used in this analysis; instead, they were used to identify relevant articles. Using this approach, the current systematic review aimed to comprehensively explore the barriers to palliative and hospice care utilization among older adults with cancer. Studies were excluded if they 1) focused on diseases other than cancer, 2) did not focus on older adults 3) did not address factors associated with palliative or hospice care utilization 4) editorial, commentaries, case studies, or research protocols.

### **Data Extraction**

The article selection process is depicted in figure 1. Two researchers (J.P. and A.T.) independently reviewed the titles and abstracts of each article to determine eligibility. The full texts of potentially eligible articles were retrieved for further review. Two researchers (J.P and A. T.) independently screened full texts of all potential articles and determined the eligibility of each article through discussion and consensus. In cases of discrepancy, the two researchers reconciled the decision and a third researcher (Y. J. or J. H.) was consulted as needed until the agreement was reached. The article selection process yielded a total of 19 final articles.

Data from the 19 eligible articles were extracted independently by two researchers (J.P., A.T.). Data extracted included authors, the country where the study was conducted, sample, predictors/participant characteristics, outcome measures, and results. A standardized data extraction form was used for data extraction. Researchers met to discuss and resolve any discrepancies in data extraction.

## **Quality Appraisal**

The quality of included studies was assessed using Fineout-Overholt's Level of Evidence.<sup>26</sup> Two reviewers (J.P and A.T.) evaluated the level of evidence of each article independently and any disagreements were brought to the group to reach a consensus.

## **Results**

The study selection process is illustrated in figure 1. The initial search yielded 1,958 articles in total from all five databases. Of these, 213 duplicate articles were excluded. Of the remaining 1,745 articles, 1,602 articles were excluded based on the review of the title and abstract. The full text of the remaining 143 articles and 9 articles identified through ancestry and search (n=152) were reviewed. A total of 19 studies met the inclusion criteria and were included in the final sample of this study. The characteristics of each study are presented in detail table 1.

## **Study Description and Level of Evidence**

The majority of studies were retrospective analysis that identified different demographic and contextual barriers associated with palliative/hospice care utilization. Among the 19 studies identified, 18 studies were quantitative, and 1 study was a mixed methods design. Among the 18 quantitative studies, 17 had retrospective designs using secondary data analysis while one study had a cross-sectional design. The mixed methods study was a combination of retrospective quantitative analysis and qualitative study. The quality of identified studies was rated on a 7-point scale using Fineout-Overholt's hierarchy of evidence<sup>26</sup> based on the study design (level 1 represented the highest level and level 7 represented the lowest level).

## **Sample Characteristics**

Study population included older adults with cancer in all studies. The sample sizes of the studies ranged from 70 participants to 282,899 participants. The majority of the studies (n=17, 89%) were conducted in the U.S., 1 study was conducted in Canada, and 1 study was conducted in the Netherlands. The major predictors of hospice/palliative care use were age, gender, race, marital status, socio-economic status, geographic residence, and health insurance. The age of the participants included were 65 and older, race of the participants examined included Caucasian/Non-Hispanic White, African American/Non-Hispanic Black, Asian, Hispanic, and Pacific Islanders. The studies examined various types of cancer, including lung cancer, breast cancer, GI cancer, colorectal cancer, prostate cancer, hematologic cancer, pancreatic cancer, liver cancer, esophageal cancer, and other cancers.

### **Types of Services Examined**

The types of services examined were either hospice care or palliative care. Four studies examined palliative care,<sup>14,27,28,39</sup> one study examined both palliative and hospice care<sup>40</sup>, while the remaining fourteen studies examined hospice care utilization.

### **Study Findings on Barriers to Palliative/Hospice Care Utilization**

In this review, the results are sorted into three categories: 1) socio-demographic barriers, 2) provider-related barriers, and 3) health-insurance related barriers.

#### ***Socio-demographic Barriers***

Seventeen of the nineteen studies reported results on the association of socio-demographic factors to palliative or hospice care utilization.<sup>14,27,29,30,31,32,33,34,35,36,37,38,39,41,42,43,44</sup> The association of each socio-



demographic factor with palliative or hospice care utilization is discussed individually below.

### **Age**

Twelve studies evaluated age as a correlate.<sup>14,27,30,32,34,35,36,38,39,42,43,44</sup> Six studies found that an advanced age served as a barrier to palliative or hospice care enrollment, and older adults were less likely to use palliative/hospice care compared to the younger counterparts.<sup>14,27,30,32,34,35</sup> In contrast, six studies found that older cancer patients were more likely to use palliative/hospice care services than younger patients.<sup>36,38,39,42,43,44</sup> Only one study found no significant association between age and use of palliative care services.<sup>27</sup>

### **Gender**

Nine studies examined the association between gender and palliative/hospice care utilization.<sup>14,32,33,34,35,36,38,42,43</sup> There was a consistent finding that males were less likely to utilize hospice care services compared to their female counterparts.

### **Race**

Thirteen studies examined the association between race/ethnicity and palliative/hospice care utilization.<sup>14,25,27,29,30,31,32,34,36,37,38,39,42</sup> Most studies consistently found that racial minority (i.e. Black, Asian, and Pacific Islanders) were less likely to use hospice care services compared to White.<sup>14,25,29,31,32,34,36,37,38,42</sup> However, one study reported that being racial minority was associated with greater odds of receiving palliative care<sup>39</sup> and two studies reported that there was no significant association between race/ethnicity and palliative/hospice care utilization.<sup>27,30</sup>

### **Marital Status**

Six studies examined the association between marital status and palliative/hospice care utilization.<sup>27,30,32,33,34,44</sup> and consistently found that unmarried individuals were less likely to use palliative/hospice care services compared to their married counterparts with the exception of two studies<sup>27,44</sup> that did not find any significant association between marital status and utilization of palliative/hospice care services.

### **Socio-economic Status (SES)**

Ten studies examined the association between SES and palliative/hospice care utilization.<sup>14,27,29,31,32,34,36,38,41,42</sup> There was a consistent finding that patients with low SES were less likely to use hospice care compared to patients with high SES. McCarthy (2003)<sup>34</sup> found that patients with higher median household income were more likely to use hospice care services compared to those with low household income. Burge et al (2008)<sup>14</sup> examined the impact of educational status on palliative/hospice care utilization and found that less educated individuals were less likely to use palliative/hospice care services. Lackan et al. (2004)<sup>32</sup> found that individuals residing in areas with low income and with lower educational levels were less likely to utilize hospice care services. Similarly, Lackan et al. (2003)<sup>30</sup> also found that women who lived in areas with low income and had lower education were less likely to be enrolled in hospice care services. Kumar et al. (2012)<sup>27</sup> also examined the association of education and use of palliative and supportive care services and found that individuals with lower educational level (college graduates) had lower use of palliative and supportive care services. Hardy et al. (2011)<sup>29</sup> found that patients in poorest SES quartiles were less likely to receive hospice care services.

### **Geographical Residence**

Nine studies examined the relationship between geographical residence (rural versus urban) and palliative/hospice care utilization.<sup>14,30,31,32,34,36,38,41,42</sup> The researchers consistently reported that individuals residing in rural areas were less likely to use palliative/hospice care services compared to individuals who resided in urban/metro areas. The reason for rural patients being less likely to use services were mostly distance to the facilities and access to those services.

### ***Provider-related Barriers***

One study reported common barriers that older adults with cancer experienced in their oncological encounters and their need for supportive care interventions. In this mixed method study, semi-structured interviews yielded an in-depth understanding of barriers in cancer/EoL care. After interviewing 14 patients and reaching a thematic saturation, authors found that *not feeling connected* to their providers hindered patient involvement or participation in decision making processes, and ultimately influences the results of communication.<sup>28</sup> Additionally, other patients reported perceived a barrier to decision making or care decision was the feeling of not being taken seriously by their providers, or feeling they *were not informed enough* about available care choices (e.g., hospice transfer) or treatment options (e.g., palliative focused treatments) for their condition.

### ***Health Insurance-related Barriers***

This category includes studies examining health insurance and other policy and reimbursement issues. Four studies compared palliative/hospice care utilization based on type of health insurance.<sup>32,34,39,40</sup> Two studies<sup>32,34</sup> compared the proportion of

hospice care utilization in older adults with cancer between managed care enrollees and fee-for-service (FFS) enrollees. Lackan and colleagues examined a total of 170,136 older adults with cancer and found that 51,345 (30.2%) patients utilized hospice care prior to their deaths, across two groups. The proportion of hospice care recipients were lower among FFS insurance (28.3%) compared to those who were enrolled in managed care (42.2%), and the difference was statistically significant ( $p<.0001$ ).<sup>32</sup> Similar findings were also reported in another study. McCarthy and colleagues examined 28,082 adults with cancer primarily patients with either lung cancer or colorectal cancer for whom hospice services were utilized.<sup>34</sup> The study found only 25% ( $n=41,888$ ) from FFS group received hospice care in the lung cancer group while 40% ( $n=6,700$ ) of managed care insurance enrollees received hospice care. In colorectal cancer group, only 19% ( $n=2,153$ ) from FFS group received hospice care while 30% ( $n=3,400$ ) of managed-care enrollees did.<sup>34</sup> Gani et al. (2018)<sup>39</sup> examined palliative care utilization in patients admitted for gastrointestinal and thoracic cancer and found that patients enrolled in other type of health insurance (Medicaid, private insurance) were less likely to receive palliative care compared to patients with Medicare (53.8%,  $p<.001$ ). Similarly, Gidwani et al. (2018) examined palliative and hospice care utilization in veterans who died of cancer in 2012 and found that patients with VA hospice care were significantly less likely to receive hospice care for at least three days compared to those who received VA-Purchased or Medicare hospice care.<sup>40</sup>

### Discussion

Palliative and hospice care services play a major role in the management of patients with cancer. Evidence suggests these services are mostly underutilized among

older adults with cancer. Therefore, a systematic review of existing literature to identify the barriers to palliative or hospice care utilization among older cancer patients was critical. To our knowledge, this is the first study to synthesize barriers to palliative/hospice care utilization in this patient population.

Among the 19 studies identified in this review, 17 studies were quantitative retrospective studies, 1 study was a cross-sectional study and 1 was mixed methods study, which are level 4 evidence. Longitudinal, prospective research on this topic is necessary to provide a higher level of evidence and evaluate the longitudinal impact of these factors. In terms of the type of services examined, four studies examined palliative care<sup>14,27,28,39</sup>, one study examined both<sup>40</sup> and the rest of the studies examined hospice care. Even though the importance and recommendations for palliative care has gained momentum in the past few years, the evidence on palliative care utilization in older adults with cancer still seems to be lacking.

In addition, the sample are largely homogeneous with 10 out of the 18 studies analyzing data from the SEER-Medicare database. While the dataset contained large sample size, the participants were from the same sample pool in the US. More studies need to be conducted from diverse population to improve the generalizability of these findings.

The socio-demographic variables examined by the studies included in this review included age, race, gender, marital status, socio-economic status, and geographical residence. Age and race were the most examined socio-demographic variables in these studies. Majority of the studies found that, racial minority (Black, Asian, Hispanics), male gender, being unmarried, low socio-economic condition, and rural residence served as

barriers to palliative/hospice care utilization. Age showed mixed results in use of palliative or hospice care. These factors help identify high-risk population to promote the use of palliative/hospice care. Notably, the findings were all from quantitative results. Future research may further examine these demographic factors in qualitative research to further examine how these factors influence the use of palliative/hospice care and identify the facilitators and barriers to the care.

Only one study examined patients' perception of provider-related barriers and identified the communication challenges that older cancer patients experience as a barrier when interacting with their providers.<sup>28</sup> The study found that patients did not feel connected to their providers and as a result had difficulties in communicating with their health care providers and participate in decision-making. Patients reported feeling not taken seriously by the providers and not informed about available care choices (i.e., palliative or hospice care).<sup>28</sup> This may contribute to lack of understanding of use of palliative or hospice care and the process to access the care. This points out the need for training for healthcare professional in communicating with family and patients with cancer. In addition, the discussion of care choice needs to be incorporated in the care process. However, data related to these provider-related barriers were obtained from qualitative interviews conducted with small sample size and only from the patient perspective. Other provider factors need to be explored by quantitative and qualitative approaches, such as provider's perception and training in palliative or hospice care, provider discipline, type of care settings, and the process of care in the context of older people with cancer. Also, to better understand the issue, provider and patient perspectives both need to be included.

Only four studies examined the influence of health insurance in palliative/hospice care utilization.<sup>32,34,39,40</sup> Two studies<sup>32,34</sup> found that the proportion of hospice care recipients were higher among those who were enrolled in managed care compared to enrollees in FFS insurance. The results may be explained by two reasons. First, the patients enrolled in managed care often tend to be younger and accepting of new technologies much earlier compared to the older counterparts. Second, because of capitated reimbursement in managed care, providers may offer hospice care more often than their FSS counterparts.<sup>32</sup> Two other studies<sup>39,40</sup> found that patients with Medicare were more likely to receive palliative care/hospice care compared to those with other insurance (Medicaid, private insurance). These findings point out the important role insurance plays in utilization of palliative/hospice care. This needs to be further examined to identify the facilitators and barriers of the care.

With the transformation of the health system, palliative/hospice care is being increasingly recognized as critical component of cancer care. This study demonstrates that there are certain factors that act as a barrier to timely and optimal utilization of palliative and hospice care. The factors associated with palliative or hospice care utilization in this review were mostly socio-demographic factors such as race, gender, marital status, socio-economic status, geographic residence and health insurance factors. Apart from these socio-demographic factors, evidence suggests there are several other patient-related, provider-related, and system-related barriers to palliative care utilization in patients with cancer. Patient-related barriers included negative perceptions and stigma around palliative care relating it to death and hopelessness, fear of having palliative care conversations with the healthcare professionals, not being

aware of availability of palliative care services, lack of referrals from physicians, lack of time, means of transportation and high expenses.<sup>27,45-47</sup>

Provider/oncologist-related barriers included equating palliative care to hospice care<sup>46-48</sup>, perception of palliative care as an alternative to cancer therapy<sup>49</sup>, belief that palliative care would decrease hope among patients<sup>46,48</sup>, perception of palliative care as defeat and personal failure<sup>47</sup> or abandoning patients<sup>46</sup>, lack of knowledge on prognostication and timing of palliative care<sup>46,50</sup>, patients' unrealistic expectations about disease trajectory, lack of balance against medical evidence versus patients' wishes<sup>50</sup>, lack of expertise and negative attitudes towards palliative care<sup>46</sup>. Oncologists reported having difficulty initiating palliative care discussions if they had close relationship with the patients or did not know the patient at all. Other barriers included focus of medical education on curative care with little or no formal training on palliative care, inexperience in palliative care conversations, and their own-life experience of having lost a relative<sup>47</sup>. As a result, oncologists often refer patients to palliative care services late in the disease trajectory when the patients experience uncontrollable symptoms and approach the end of life.<sup>46,51</sup>

Other health-system related barriers included lack of palliative care specialists or palliative care services in their facility, focus of hospitals toward curative treatment, lack of consensus in the healthcare team regarding initiation of palliative care services, lack of available space in the facility to initiate palliative care conversations<sup>47,52</sup>, and space limitations in in-patient palliative care units.<sup>52</sup>

Previous studies have identified the name "palliative care" in itself can serve as a barrier to palliative care referral among oncologists.<sup>53</sup> Oncologist also perceived the



name “palliative care” decreases hope and causes distress in patients with cancer and their families.<sup>53</sup> Researchers who examined the impact of name change of “palliative care” to “supportive care” in palliative care consultations in patients with cancer found that the term “supportive care” would be more preferable to patients with cancer and their families.<sup>53,54</sup> The name change led to greater number of palliative care consultations resulting due to increased inpatient referrals<sup>52,53</sup> finally leading to longer overall survival duration from palliative care consultation.<sup>52</sup> However, these studies were excluded from this review because they did not specifically focus on older population. Future studies should be conducted to understand older adults with cancer and their family’s perspectives on the barriers to palliative and hospice care utilization, providers perspective on palliative care referrals and discussions focused on older adult with cancer, and system-related barriers in relation to providing palliative care to older adults with cancer.

### ***Study Implications***

The findings of this review have some implications in policy and practice. Older adults with cancer are at risk for underutilization of palliative and hospice care services. Older adults who are single, ethnic minority, lower income, less educated, and live in rural areas are even at higher risk to underutilize palliative or hospice care. Therefore, older adults with cancer who may benefit from palliative care services should be identified and referred early in the disease trajectory. Providers and patients have communication challenges regarding open discussion about palliative care services, which leads to late referral and underutilization of these services. In addition, language and cultural barriers can be a major barrier to palliative/hospice care discussions. It is

difficult for providers to assess patients' understanding of medical information when they speak a different language.<sup>55</sup> The inability to communicate in English or limited English proficiency can hinder patients with cancer from obtaining appropriate medical attention because information delivered or conversations in cancer care are often complex, confusing and distressing in nature.<sup>56,57</sup> Finally, ineffective and poor communication may lead to feelings of distrust and hopelessness in cancer patients leading to non-adherence to cancer treatment and dissatisfaction with care provided.<sup>57</sup>

Therefore, interventions are needed to address provider-related barriers and communication challenges between the two parties and improve the utilization of palliative and hospice care services. Providing education to providers and patient population is important to improve awareness and increased utilization of palliative and hospice care services. FFS enrollees tend to less likely to use palliative or hospice care. The reimbursement of FFS on use of palliative or hospice care needs to be further examined and payment gaps need to be identified. Better reimbursement policies need to be formulated in order to offer palliative and hospice care services in a lower cost to targeted older oncology patients.

Findings from this systematic review can provide directions to future research. First, this review found that most studies on this topic are retrospective secondary analysis and most of them are from the same dataset. In addition, barriers from the perspectives of patients and providers are lacking. Evidence from prospective studies would provide stronger evidence. Therefore, future studies should be prospective and include qualitative studies to understand patients' perspectives on the barriers to palliative and hospice care utilization in this patient population. Qualitative studies from caregivers,

family, and patients would provide greater insight and voices from all parties to better understand the barriers of care.

Second, this systematic review points out the need to explore more correlates of palliative/hospice care use. Since palliative or hospice care utilization can be multifaceted and complex, future research should examine additional variables that can affect the utilization of palliative or hospice care utilization. For patient characteristics, health literacy of the patient and their families, perceptions of palliative/hospice care and social support are potential correlates that are worth exploring. There are only a few studies examining provider-related or insurance-related factors. Future research may further explore care providers' perception and knowledge on palliative care as well as patients' access and financial barrier to the services.

Third, many of the included studies were relatively outdated. With the changing healthcare system, advancement of palliative/hospice care services and changes in health-insurance related policies, the findings of many of these studies may not translate to the current situation. Therefore, future studies need to be focused on older adult populations to compare the findings.

### ***Strengths and Limitations of the Study***

One major strength of this review is that the search, extraction, and writing of the article followed the PRISMA guidelines. The thorough literature search and careful systematic extraction of data by independent reviewers ensured the inclusion of all relevant studies. Through categorizing study design, sample, and outcomes for palliative and hospice care utilization, this systematic review provides direction for future projects.

While this review was conducted in a rigorous approach, it has some limitations. The majority of the included studies were retrospective secondary analysis. There was a lack of prospective and qualitative studies that examined patients with cancer and their families' perspectives on barriers to palliative/hospice care utilization. In addition, except for two studies, almost all studies were from the US. The two studies from outside the US were from countries that have advanced health care systems and have palliative care services available, therefore limiting the generalizability of the findings worldwide especially in the developing countries where palliative care is still at its infancy. The location of research is important for this topic because the availability of palliative/hospice care services, cost, and public acceptance of palliative/hospice care may differ for between countries and cultural contexts. As stated earlier, various studies that identified patient-related, provider-related and health-system related barriers were excluded from this review because they did not focus on older adults with cancer. Finally, case studies, review papers, editorials and commentaries were excluded in this systematic review leading to a small number of articles.

To address these limitations, future research should examine the barriers to palliative/hospice care utilization care from patients and caregivers' perspectives prospectively in a larger scale together with other parameters and determinants of health including symptom burden, illness perception, access to palliative care services, caregivers support/social support, self-efficacy, satisfaction with care, and quality of services provided, as well as patients' perception on barriers to care outcomes when palliative care is applied to older adults with cancer. Finally, studies should also be conducted in less developed countries with less advanced health care systems.

## **Conclusion**

With the aging of the population, the number of older adults with cancer is increasing globally and it poses new challenges to the delivery of cancer care and palliative and hospice care services. With the increasing number of older adults with cancer, the unmet needs of cancer patients and families will be increasing jeopardizing their quality of life. Therefore, more research is needed focusing on geriatric population who have unique care needs with the increase in number of chronic conditions topped with cancer.

This systematic review identified various socio-demographic, provider-related and health insurance related barriers to palliative and hospice care utilization among older adults with cancer. Patient-related barriers can guide the identification of at-risk population for underutilization of hospice and palliative care. Interventions are needed to address provider-related barriers such as communication challenges. Nevertheless, before findings can be generalized, future research may further examine this topic through prospective studies in a larger scale, with a sound theoretical framework.

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### **Description of authors' roles**

Study concepts: J Parajuli, A Tark, Y-L Jao & J. Hupcey

Study design: J Parajuli, A Tark, Y-L Jao & J. Hupcey

Data acquisition: J Parajuli, & A Tark

Quality control of data and algorithms: J Parajuli, & A Tark

Data analysis and interpretation: J Parajuli, A Tark, Y-L Jao & J. Hupcey

Statistical analysis: J Parajuli, A Tark, Y-L Jao & J. Hupcey

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Manuscript review: J Parajuli, A Tark, Y-L Jao & J. Hupcey

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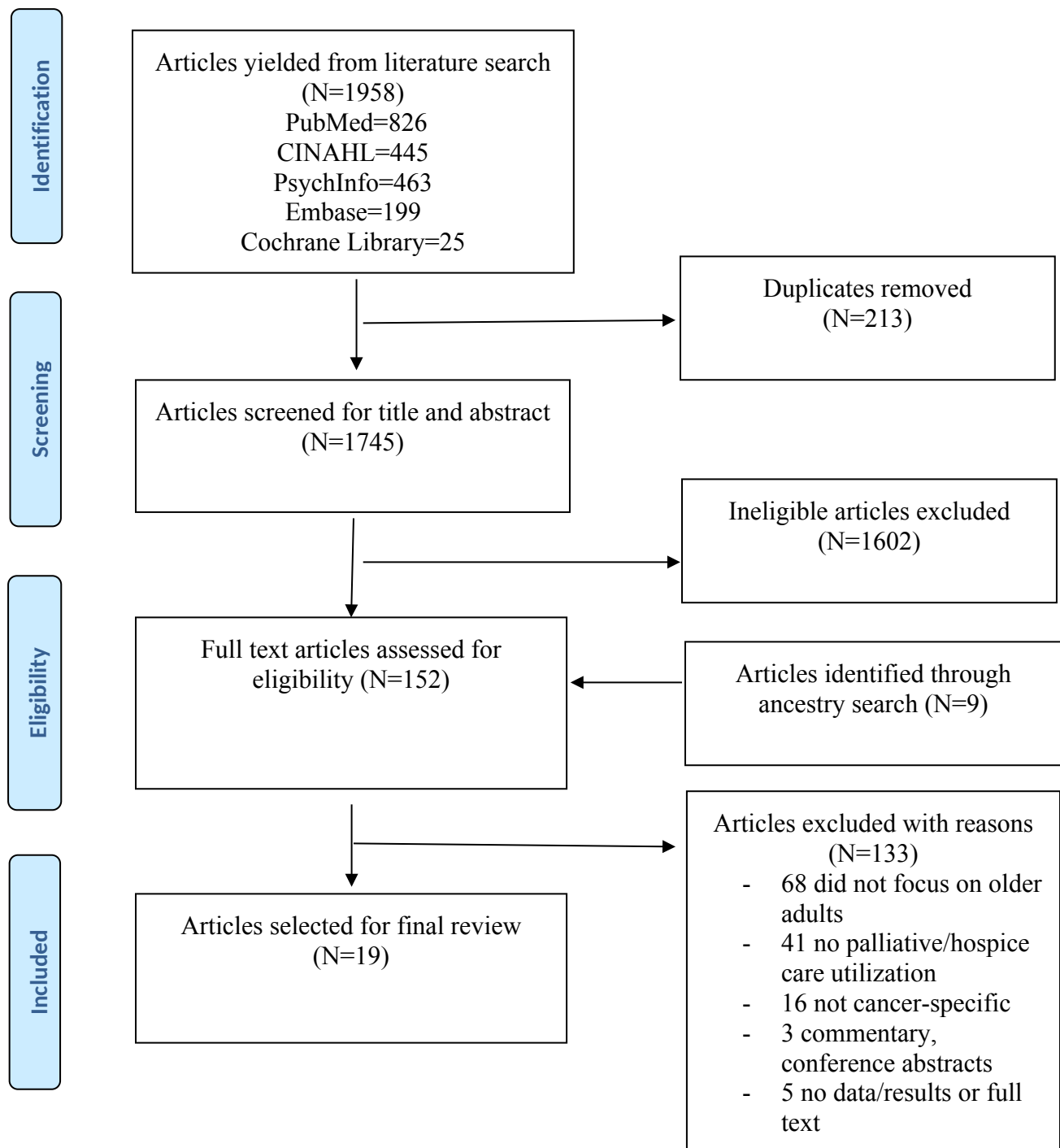
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**Figure 1.** PRISMA flow diagram





**Table 1:** Description of Studies Included

<b>Article/ Country</b>	<b>Study design</b>	<b>Sample</b>	<b>Predictors</b>	<b>Type of service</b>	<b>Results</b>
Burge et al., (2008) Canada	Retrospective population-based study (Secondary analysis of linked individual level information)	7,511 patients who died with cancer between 1998 and 2003.	Age, gender, race, SES, geographic residence	Palliative care	Older subjects were significantly less likely than those less than 65 years of age to be registered with a PCP, particularly those aged 85 years and older (adjusted OR: 0.4; 95% CI: 0.3–0.5).
Gani et al., (2018) United States	Retrospective cross-sectional analysis (data from NIS)	282,899 patients were identified who met the inclusion criteria	Age, race, health insurance	Palliative care	Among all patients, 8.5% received a PC consultation during their admission. Patient age (age $\geq 75$ years: OR=2.54) was associated with greater odds of receiving PC ( $p < 0.05$ ) and a member of a racial minority (27.6% vs. 30.2%, $p < 0.001$ ). Individuals with Medicare were more likely to receive PC (53.8 %, $p < .0001$ ).
Gidwani et al., (2016) United States	Retrospective analysis (administrative data for veterans aged 65 years or older).	11,896 veterans aged 65 years or older with cancer who died in 2012	Health insurance, type of cancer	Palliative and hospice care	Most veterans (71%) received hospice care, whereas only 52% received palliative care. Patients with VA hospice care significantly less likely to receive hospice care for at least three days compared to those who received VA-Purchased or Medicare hospice care.

# PALLIATIVE AND HOSPICE CARE IN OLDER ADULTS

Hardy et al., (2011)	Retrospective analysis (SEER Medicare database)	117,894 individuals aged 66 and older with non-small cell lung cancer (NSCLC) who received hospice services in the last 6 months and died between 1991-2005.	Race, SES	Hospice care	In urban area blacks (OR=0.79; 95% CI=0.63-0.82), Asian/Pacific Islanders (OR=0.42; 95% CI= 0.39-0.46) and Hispanics (OR=0.81; 95% CI= 0.73-0.91) were less likely to receive hospice services compared to whites. In rural areas blacks were 21% less likely to received hospice services (0.79; 95% CI=0.63-0.98). Patients in lowest SES quartile were 7% less likely to receive hospice services (OR=0.93, 95% CI=0.86-1.00).
Kumar et al., (2012)	Cross-sectional	313 patients with a primary diagnosis of cancer seen in 3 outpatient oncology clinics at one academic cancer center	Age, race, marital status, SES	Palliative care	50% of the participants had not used palliative and supportive care services.
Miesfeldt et al., (2012)	Retrospective analysis (Medicare claims data)	235,821 Medicare parts A and B, fee-for-service patients dying with poor prognosis cancer	Age, gender, race	Hospice care	Older age (OR=0.92; 95% CI 0.89-0.95), female gender (OR=0.84; 95% CI 0.81-0.86) and black race (OR 0.81, 95% CI 0.76-0.86) was associated with late hospice enrollment.
United States					
McCarthy et al., (2003)	Retrospective analysis (SEER Medicare database)	62,117 patients with the diagnosis of lung or colorectal cancer	Age, gender, race, marital status, SES, geographic residence,	Hospice care	20% entered hospice within 1 week of death, 6% entered more than 6 months before death. Factors with later hospice enrollment: being male, non-white, non-black race, having fee for service insurance, residing in a rural community. Also associated with shorter stays in hospice.
United States					

# PALLIATIVE AND HOSPICE CARE IN OLDER ADULTS

			health insurance		
Lackan et al., (2003)	Retrospective analysis (SEER Medicare database)	25,161 Female, aged 65 and older, living in one of SEER areas, diagnosed with breast cancer.	Age, race, marital status, SES, geographic residence	Hospice care	20.7% used hospice care before they died. Inverse relationship between use of hospice and age ( $p<0.001$ ). Higher use among married patients ( $p<0.001$ ). No differences in use by ethnicity. Significant differences in hospice usage based on geographic residence, income and educational level ( $p<0.001$ ).
Lackan et al., (2004)	Retrospective analysis (SEER Medicare database)	170,136 individuals aged 67 and older diagnosed with breast, colorectal, lung, or prostate cancer from 1991 to 1996 and who died between 1991 and 1999.	Age, gender, race, marital status, SES, geographic residence, health insurance	Hospice care	The rate of hospice utilization was higher for subjects who were younger, married, female, non-Hispanic white, living in urban areas, diagnosed with lung or colorectal cancer, and living in areas with higher income and education levels.
Lackan et al., (2005)	Retrospective analysis (SEER Medicare database)	71,948 patients diagnosed with breast, colorectal, lung or prostate cancer from 1991-1996, and died between 1991-1999	Gender, marital status, geographic residence	Hospice care	Currently married (OR=1.36, 95% CI=1.28-1.45) or ever married (OR=1.23, 95% CI=1.16-1.31) subjects were more likely to use hospice than never married subjects. A significant interaction between marital status and gender ( $P<.001$ ) was observed.
Nayar et al., (2014)	Retrospective analysis (SEER Medicare database)	91,039 Medicare beneficiaries who died in 2008	Age, gender, race, SES, geographic residence	Hospice care	Racial minority were less likely to have ever used hospice or be enrolled in hospice in last 3 days of life compared on non-Hispanic Whites. In addition, patients with low SES were less likely

# PALLIATIVE AND HOSPICE CARE IN OLDER ADULTS

					to ever use hospice or be enrolled in hospice care within last 3 days compared to patients with high SES.
Ngo-Metzger, (2003)	Retrospective analysis (SEER Medicare database)	184,081 patients who died of primary lung, colorectal, prostate, breast, gastric, or liver cancer between 1988 and 1998.	Race, geographic residence	Hospice care	After adjustment, patients who were Asian American (OR=0.67; 95% CI=0.62 to 0.73) and born abroad (OR=0.90; 95% CI=0.86 to 0.94) were less likely to use hospice care than were white patients.
United States					
Noordman et al., (2017)	Mixed methods (quantitative secondary data analysis and qualitative interviews)	Patients with the diagnosis of cancer (n=126) of which 70 were aged 65 and older and 56 were younger patients (aged 18-65)		Supportive care interventions	Barriers and facilitator related to attributes of themselves (impact of dx, feeling modest or shy, uncomfortable with provider especially intimate issues, forgetting questions self-efficacy, feeling sick), provider (taking patient seriously, not feeling connected, topics or emotions not being discussed, lack of information) and healthcare system (time restriction, inefficient communication between different providers).
Netherland					
Saito et al., (2011)	Retrospective analysis (SEER Medicare database)	7879 patients aged 65 and older who died of lung cancer from 1991 through 1999	Age, gender, race, geographic residence, SES	Hospice care	Being older, female, non-Hispanic white, residing in urban areas and higher SES were associated with hospice use.
United States					
Sharma et al., (2016)	Retrospective analysis (chart review)	567 veterans who died with advanced cancer between 2002 and 2009	Age, race, marital status, type/location of cancer	Hospice care	Older adults had earlier referral to hospice care (mean DOR: 47.3, p = 0.015), and longer stay with hospice (mean LoS: 32.5, p = 0.007).
United States					

# PALLIATIVE AND HOSPICE CARE IN OLDER ADULTS

Shugart et al., (2008)	Retrospective cohort study	13,120 Medicare decedents with lung cancer	Age, gender	Hospice care	Women were more likely to use hospice services (14% more likely than men). Older cohorts were significantly more likely to have used hospice services in their last years of life.
United States					
Smith et al., (2009)	Retrospective analysis (SEER Medicare database)	40,960 fee-for-service (FSS) Medicare beneficiaries aged 65 and older with advanced cancer	Race	Hospice care	Compared to Whites (42%), hospice enrollment was lower for black (36.9%), Asian (32.2%), and Hispanic (37.7%) patients.
United States					
Trombanton et al., (2018)	Retrospective analysis (SEER Medicare Database)	6449 cancer patients of which 3597 (55.8%) enrolled in hospice.	Age, gender, race, SES, geographic residence	Hospice care	Among hospice-enrolled patients, 31.4% enrolled in the last 7 days of life. Patients who were older, female, with stage IV disease, or those with higher socioeconomic status were more likely to enroll in hospice.
United States					
Watanabe-Galloway et al., (2016)	Retrospective analysis (Medicare claims data)	34,975 beneficiaries with colorectal cancer who died in 2008	Geographic residence, race, SES	Hospice care	Beneficiaries in rural counties were less likely to ever use hospice (OR = 0.78) compared to those in metropolitan counties after adjusting for demographic factors. Beneficiaries from racial/ethnic minority groups and lower SES were less likely to ever use hospice.
United States					

Note: CI: confidence interval; OR: odds ratio; PCP: primary care provider; NIS: National Inpatient Sample; SEER:

Surveillance, Epidemiology, and End Results; SES: socio-economic status