

REVIEW

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Factors Influencing the Quality of Life (QOL) of Advanced Cancer Patients in Home-based Palliative Care (HBPC): A Systematic Review

Ajay Kumar Kondeti¹, Kesava Ramgopal Adavikolanu^{1*}, Soorej Balan Kaliyath¹, Yamini Marimuthu², Haveela Mary Nannepaga¹, Gopi Krishna Shyam¹, Shobhan Babu Varthya³

Abstract

Context: Despite the widespread recognition of the need for new palliative care models to better serve advanced cancer patients at the end of life, little importance is given to assessing the effectiveness of homecare models. **Objective:** This systematic review aims to summarize factors influencing the quality of life (QOL) of advanced cancer patients in home-based palliative care (HBPC) being adopted worldwide. **Methods:** Following the PRISMA guidelines, electronic databases such as MEDLINE, Cochrane, EMBASE, and Scopus databases from 2000 to February 2024 were systematically searched using predetermined search terms of “quality of life”, “home-based palliative care” as well as “advanced cancer”. Studies with less than ten subjects, scoping reviews, conference abstracts, and that adopted poorly validated QOL questionnaires were excluded. **Results:** Twenty-two (22) studies from both developed and developing countries were included in the narrative synthesis. 45.4% were cross-sectional, 27.2% were prospective cohort studies, 13.6% were retrospective cohort studies, and 18.1% were RCTs or quasi-experimental studies. Around 33 QOL factors were studied with 16 different types of QOL instruments. Advanced cancer patients who practiced spirituality, female gender, were married, had satisfaction with care, and preferred home as a place of death showed higher QOL scores. Older patients, aware of cancer diagnosis, poor performance status, high pain score, symptom distress, and psychological distress were associated with a poor QOL. **Conclusion:** Various factors affect QOL among cancer patients in HBPC. Hence it shows the importance of interventions to improve QOL and their rigorous implementation. With the widespread adoption of multi-disciplinary home care palliative programs, palliative care services to advanced cancer patients can be delivered readily which may be cost-effective.

Keywords: Quality of life- Home-based Palliative care- Advanced cancer- Systematic review

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Introduction

Cancer is one of the leading causes of morbidity and mortality. Worldwide, an estimated 19.3 million new cancer cases and almost 10 million cancer deaths occurred in 2020. According to GLOBOCON, the nations categorized as “Low or Medium Human Development Index (HDI)” would experience the highest relative rises in cancer incidence by 2040 [1]. Most cancers in these nations are often diagnosed at advanced stages when treatment choices are scarce or unavailable [2]. Improving quality of life (QOL) is the main objective of palliative care (PC) for these advanced cancer patients, who no longer react well to curative treatments. It is also a crucial result of evaluating how well the care is working [3].

An estimated 56.8 million people require palliative care annually, 25.7 million of whom are in their last year of life. However palliative care services are being provided to only 14% of needy patients worldwide [4].

Cancer patients’ quality of life is a multifaceted notion that includes managing their symptoms as well as their physical, psychological, social, and spiritual well-being [5]. By facilitating a calm progression of the disease, addressing the latter stages of life, and providing a dignified death, the holistic approach to palliative care can enhance the quality of life for these patients and their families [6]. These advanced cancer patients receive palliative care via a variety of modalities, including home care, hospice care, inpatient treatment, and outpatient care. An effective PC strategy can provide appropriate

¹Department of Radiation Oncology, All India Institute of Medical Sciences (AIIMS), Mangalagiri, India. ²Department of Community and Family Medicine (CFM), All India Institute of Medical Sciences (AIIMS), Mangalagiri, India. ³Department of Pharmacology, All India Institute of Medical Sciences (AIIMS), Jodhpur, India. *For Correspondence: kesavaiims@gmail.com

support and symptom control for cancer patients [7]. The cost-effectiveness and improved patient satisfaction associated with home-based palliative care (HBPC) treatments have led to an increase in their popularity globally among various palliative care delivery system models [8]. Home care enables a patient to reside with family and provides a supportive family environment that in turn lowers the cost for the health care system [9].

However, little is known about the quality of life (QOL) of advanced-stage cancer patients who get care at home because the majority of current studies have focused on examining the association between awareness of the disease and the QOL of hospital inpatients and outpatients only [10]. To our knowledge, very few studies done to assess the factors influencing the quality of life (QOL) in home-based palliative care (HBPC) settings.

To close this gap, this study aimed to assess the quality of life (QOL) of advanced-stage cancer patients receiving home-based palliative care (HBPC) and to evaluate the factors influencing their quality of life.

Materials and Methods

We registered our systematic review with PROSPERO (CRD42024529787) and adhered to the standard protocol for systematic reviews as outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [11].

Search strategy

We searched the databases MEDLINE, Cochrane, Embase, and Scopus to find studies, as per the Peer Review of Electronic Search Strategies (PRESS) guidelines. “Quality of life,” “cancer,” and “home-based palliative care” were among the search terms used. To guarantee a thorough examination of the material and to obtain all relevant evidence, we employed a broad search approach. By carefully examining the references in the papers we were able to collect, we enhanced our search approach. We limited the scope of our search to English-language publications released between January 1, 2000, and February 12, 2024.

Eligibility criteria and study selection

The selection of the research was done by two reviewers. Studies that satisfied the following inclusion requirements—adult patients (≥ 18 years) with advanced cancer stage, in HBPC, and with QOL/QOL domains being assessed as the outcome of interest—were taken into consideration for an initial evaluation. The American Joint Committee on Cancer staging standards were used to identify the advanced cancer stage [12]. The following were the main outcomes: (1) QOL score as determined by QOL questionnaires, such as the Functional Assessment of Cancer Therapy-General (FACT-G) or the Quality of Life Questionnaire (EORTC-QLQ); (2) Quality of Life dimensions, such as functional scales (physical, role, emotional, cognitive, and social functioning) and symptoms scales (dizziness, pain, sleeplessness, fatigue, nausea, and vomiting, appetite loss, constipation, diarrhea, and financial issues...), etc, or (3) clusters of symptoms

or spirituality, or individual symptoms (such as anxiety and depression).

Studies with fewer than ten patients, qualitative or pilot studies, reviews, conference abstracts, research including patients with psychological illnesses, and studies utilizing poorly validated QOL questionnaires were all excluded from consideration. Following the elimination of duplicates, titles, and abstracts were independently screened by KAK and AKR, and the full text of the chosen papers was evaluated to ascertain conformity with the inclusion criteria. Disputes were resolved through dialogue until an agreement was achieved.

Data extraction and quality assessment

A standardized data extraction matrix was utilized by the two reviewers to independently extract data from each study, including the year of publication, region, country, study design, population demographics, study sample size, cancer type, HBPC, reported factors linked to QOL/QOL domains, score of QOL/QOL domains, reported outcome of interest, and study quality assessment.

A narrative synthesis presents the factors that were positively or adversely associated with QOL/QOL dimensions. Results such as the overall mean QOL of the FACT-G, overall well-being subscales, or QOL score as determined by the global health status of the EORTC-QLQ were extracted. When available, information on individual symptoms, symptoms/spirituality clusters, and other QOL dimensions was retrieved.

We performed the critical appraisal using the Newcastle-Ottawa Quality Assessment Scale (adapted for cross-sectional studies), the Newcastle-Ottawa Quality Assessment Scale for cohort studies [13], and the JBI Critical Appraisal Checklist for quasi-experimental studies [14], as detailed in more detail in Supplement file.

Results

Study selection

After duplicates were removed from the 468 publications that the systematic search turned up, 257 articles (Figure 1) could be screened for inclusion and exclusion based on their titles and abstracts. 198 articles were removed because they didn't fit the inclusion requirements. 37 articles were eliminated after reviewing all 59 of the articles in full. In total, 22 articles were included.

Study characteristics and quality assessment

The chosen studies included an analysis of 58 [15] to 690 [16] patients with advanced cancer. Cross-sectional studies accounted for ten of the studies, with nine cohort studies and three quasi-experimental studies following. In terms of geography, the majority of research ($n = 11$) came from Asia, then Europe ($n = 6$), America ($n = 2$), Africa ($n = 5$), and Australia ($n = 1$) (Supplementary Table 1). China and India were countries with the highest number of studies (3, and 3, respectively).

The quality assessment showed that from 10 cross-sectional studies, most studies ($n=6$) had a fair quality and the rest of the studies ($n=4$) had good/

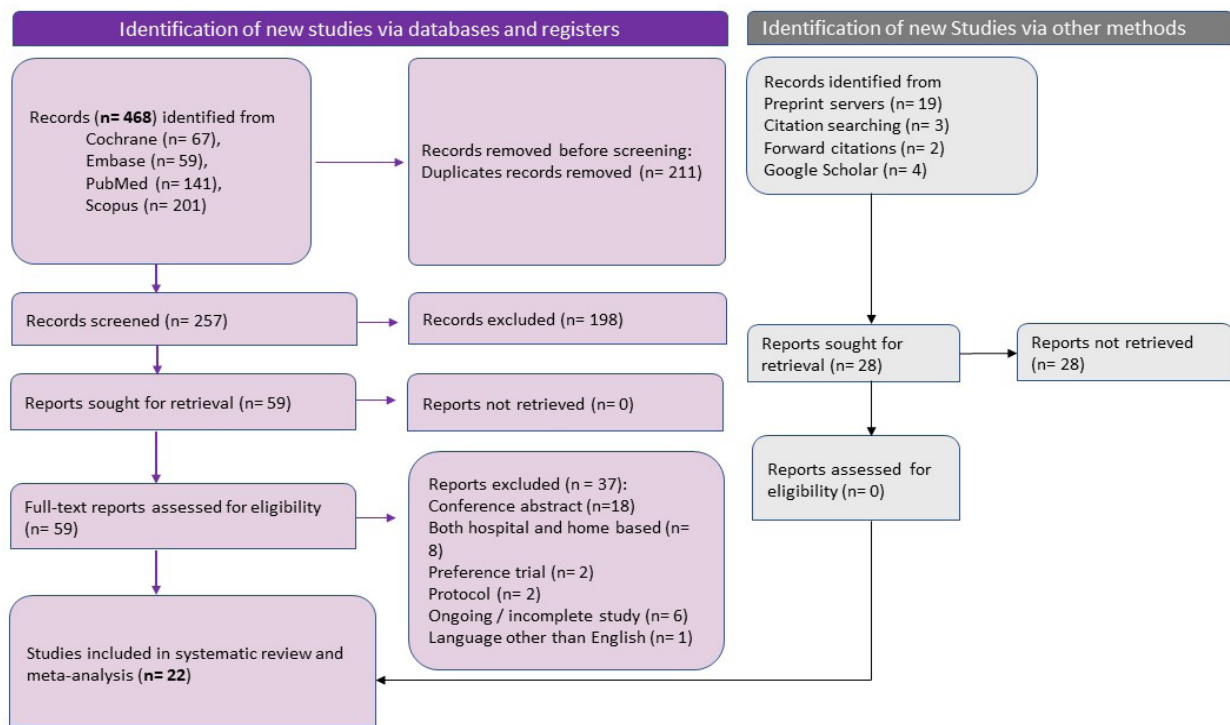


Figure 1. PRISMA Flow Diagram of the Study Collection. Source Moher et al. [11]

high-quality scores. Similarly, out of 9 cohort studies, the majority (n=5) of studies [16,18-19,27,30] had moderate quality, with three studies [5,28-29] having low quality, whereas one study [25] had high-quality critical appraisal scores. The three quasi-experimental studies had a moderate quality assessment (Supplementary file).

Factors associated with QOL in HBPC

Around 33 factors were reported in the 22 included studies (Supplementary Table 2). These studies showed that factors assessed and linked to QOL/QOL domains in countries varied across the continents (Table 1).

Sociodemographic factors

The patients' age ranged from 19 [17] to 96 years [18]. When compared to other age groups, older patients were associated with a poor QOL which may be related to poor physical status and performance scores, as they usually prefer home care [15, 18-22].

The reported gender proportions varied among the studies. While fourteen studies (66.67%) showed that the proportion of female patients was higher than that of male patients [15-16, 19-26, 29-30, 32-33], seven studies (33.33%) demonstrated the opposite [17-18,27-28,31,34-36]. One study didn't report gender data [5]. Out of these, three studies [20,24,28] reported that female cancer patients had better QOL/QOL domains than male patients. Women were more expressive in their needs and more willing to seek and receive help from others compared to men. Consequently, they often received more support, which may contribute to a better QOL [22].

Another sociodemographic factor marital status (married/ever been married), is linked to better scores in QOL/QOL domains. Research revealed that patients who

shared a home with their parents, spouse, kids, or other family members had lower rates of anxiety and depression and a better quality of life than those who lived alone. During their illness, patients who were married received financial and psychological support, which improved their quality of life [15, 28, 29, 35].

One included study that assessed the association between Education status and QOL reported that patients having low education standards tended to have poor QOL [21]. Studies reported that cancer patients with lower levels of education frequently have lower socioeconomic status (SES) in society. Consequently, individuals were more likely to exhibit depressive symptoms, have a low quality of life, and have a limited grasp of their illness [37]. Another sociodemographic factor i.e., place of residence was assessed in one study that assessed the association between residency and QOL and reported that patients living in central Italy tended to have better QOL [20].

Spirituality

Four included studies, one from Europe [20], America [24], Asia [32], and Africa [33] found an association between spirituality and higher QOL/QOL domain scores. This could be explained by a study that found the majority of patients thought spirituality was a helpful coping technique, supported them during cancer treatment, helped them in stressful situations, and should be considered when being evaluated by medical professionals [38]. Research conducted in Asian nations revealed that personal spiritual practices such as prayer, meditation, and reading religious texts were associated with improved hope and a happier mood as well as improved quality of life and spiritual well-being for patients. Those patients with no religious affiliation tend to exhibit poor QOL [39].

Table 1. Factors associated with the QOL/QOL Domain Outcomes

S.No	Factors	Better QOL and/or QOL domains
1	Gender (female vs male)	20,24,28
2	Marital status (married vs other)	15,28,29,35
3	Residence (developed vs under developed)	20
4	Physical status (better vs poor)	20,25
5	Social status (better vs poor)	20,32
6	Spirituality (spiritual or non believer)	20,24,32,33
7	Symptom control (declined symptom score or not)	24
8	Family support (high vs low support)	24
9	Quality Home care (high access or low access)	25,26
10	Duration of homecare (adequate or not)	15,30
11	Frequency of home care visits (adequate or not)	30
12	Satisfaction with care (high vs low score)	23,26,31
13	Complementary & Alternate Medicine (CAM) (yes or no)	22
14	Place of death (home vs others)	16,19,26,29,30
15	Multidisciplinary Home care (yes or no)	30
S.No	Factors	Poor QOL and/or QOL domains
1	Age (>65 years vs other)	15,18, 19,20,21,22
2	Education (Illiterate vs Literate)	21
3	Tumor site (gastro intestinal vs others)	19,35
4	Cancer stage (advanced vs early)	29,30
5	Cancer diagnosis awareness (aware vs not aware)	17,18,21,28
6	Performance status (low vs high score)	5,20,29,32
7	Caregiver (informal vs formal)	34
8	Age of Family caregiver (> 60 years)	29
9	Dependency (high vs. low level)	33
10	Physical status (poor vs better)	17,30
11	Social status (poor vs better)	25,34
12	Psychological status (poor vs better)	17,25,31,33
13	Financial burden (high vs. low level)	21,25,26,34,35
14	Pain intensity (high vs low score)	5,25,27,29,31,34
15	Pain medication unavailability (yes or no)	19
16	Fatigue (high vs low score)	27,31
17	Dyspnea (high vs low score)	27
18	Depression (high vs low score)	25,31
19	Drowsiness (high vs low score)	25,31
20	Symptom distress (high vs low score)	25,28,30,33

Satisfaction with care

Three studies analyzed the association between satisfaction with care provided during HBPC and QOL and reported better scores in QOL/QOL domains [23,26,31]. Home-based palliative care can help in good symptom control for patients suffering from advanced cancer. It can result in the satisfaction of the patients and caregivers throughout and in grief [23]. Other care-related factors like quality of home care delivered [25,26], duration of homecare given [15,30], frequency of home care visits [30], and Multidisciplinary Home care [30] showed a trend towards better scores in QOL/QOL domains though in limited studies.

Home as a preferred place of death

Five included studies showed that better QOL/QOL domain scores were associated with patients who preferred home as a place of death [16,19,26,29,30]. Studies showed that meeting patients' preferences for place of death is an indicator of quality palliative care [40]. This requires an awareness of patients' and their families' preferences, often established through care planning discussions [41]. Preference for home death, low functional status, staying with relatives, extended family support, as well as availability and intensity of homecare services, such as home-based palliative care, were strongly associated with home death [42]. Besides providing support for patients' physical and psychosocial needs, home-based palliative

care coordinates referrals to support services. This reduces unnecessary care setting transitions at the end of life [43], thereby increasing the likelihood of home death [44,45].

Cancer diagnosis awareness

Four research studies investigated the awareness of diagnoses [17,18,21,28]. In some studies, between 17.5% and 50% of patients, that is, a low percentage of patients only knew what their diagnosis was [17,46, 50]. Compared to patients who knew their illness, those who were uninformed of it were more likely to function better emotionally and physically as well as have a higher quality of life overall [17,48].

One study showed that patients' outlooks became more optimistic as a result of the information withholding, and their will to combat the illness was boosted [17]. It was likely that cultural factors had a significant influence on this non-disclosure. Being ignorant of a cancer diagnosis may be linked to improved physical and emotional functioning since in some Asian cultures, receiving a cancer diagnosis is a taboo subject and patients frequently feel humiliated and ashamed of their illness [17, 47, 48].

Other cancer-related factors like Tumor site [19, 35] and advanced cancer stage [29, 30] showed a trend towards poor scores in QOL/QOL domains though in limited studies.

Financial burden

Five included studies showed that poor financial status is associated with poor QOL/QOL domains [21,25,26,34,35]. Studies showed that the increased costs of health care, and in particular the high costs of specialized care for the dying, have brought further attention to the need to scrutinize the costs of end-of-life medical care. Furthermore, in addition to being costly, acute care at the end of life is not always the preference of the dying patient [50].

One included study reported factors like adequate family support in this group of patients resulting in better QOL/QOL domains. In developing countries, often a joint family system exists, which leads to better QOL in comparison to the predominantly nuclear nature of families in developed countries [24].

Performance status

Four included studies showed that a high score for poor performance status is associated with poor QOL/QOL domains [5,20,29,32]. One included study reported that a low score for performance status may result in their inability to perform enjoyable and usual activities compared to others, resulting in poor QOL scores. Cancer patients at this level of their illness lost their independence, felt tired, and were not able to participate in pleasant activities. These conditions also affect their social life [32].

Other relevant factors like physical status varied among the studies, with some of the studies showing positive [20,25] and others showing negative trends [17,30]. Likewise, social status showed a varied trend with positive [20,32] and negative [25,34] associations with QOL/QOL domains.

Psychological status

Four included studies showed that a high score for poor psychological status is associated with poor QOL/QOL domains [17,25,31,33]. Studies showed poor psychological condition might decrease one's hope and peace, and lead to an increase in physical pain, risk of suicide, and poor QOL. Also, other psychological domains of QOL e.g., being afraid of the future, feeling sad, and feeling a burden to others might intertwine with depression and anxiety [49].

Pain intensity

Six included studies showed that a high score for pain experienced is associated with poor QOL/QOL domains [5,25,27,29,31,34]. Studies reported various causes for pain in advanced cancer patients such as local pain, malignant pain syndrome, non-malignant pain syndromes, neuropathic syndromes, and also combination of syndromes [51]. Patients experience chronic non-malignant pain from osteoarthritis and other causes [52]. Pain surveys reported various prevalences of pain among advanced cancer patients, one survey reported up to 57% of patients with cancer reported pain due to their disease, and, of those with pain, 69% rated their worst pain at a level that impaired their ability to function thus impairing the QOL [53]. Pain never was a solitary symptom, and should be considered a marker for the presence of other symptoms. Patients with intense pain are at increased risk for experiencing other severe symptoms such as dry mouth, dyspnoea, lack of energy, weight loss, etc. [54].

Hence, routine comprehensive pain assessment may identify a significant fraction of patients who urgently require intensive symptom palliation. One included study reported poor QOL due to inadequate availability of pain medications [19].

Symptom distress

Four included studies showed that high symptom distress is associated with poor QOL/QOL domains [25,28,30,33]. Studies showed fatigue (weakness) was the most prevalent symptom followed by pain, poor appetite, poor mobility, constipation, dyspnea, sore or dry mouth, nausea, drowsiness, vomiting, etc. [28]. Various included studies reported individual symptoms like fatigue [27,31], dyspnea [27], depression [25,31], and drowsiness [25,31] showed a trend towards poor scores in QOL/QOL domains though in limited studies.

One included study reported that factors like symptom control in this group of patients resulted in better QOL/QOL domains [24]. Another included study reported that using Complementary & Alternate Medicine (CAM) in this group of patients resulted in better QOL/QOL domains [22].

Caregivers' factors

Various included studies reported individual caregivers' factors like Family caregiver [34], old age of Family caregiver [29] and care dependency [33] showed a trend towards poor scores in QOL/QOL domains though in limited studies. The care being provided by family caregivers often results in a psychological burden on both

patients and FCs. They tend to suffer in relation to each other as dyad [34].

Discussion

To our knowledge, this is the first review to systematically identify the factors associated with quality of life (QOL) among advanced cancer patients in a Home-based palliative care (HBPC) setting. In our review, we included studies from the developing as well as the developed world. The findings point towards a range of factors associated with QOL in this population.

In our review, advanced cancer patients who practiced spirituality, female gender, were married, had satisfaction with care, and preferred home as a place of death showed higher QOL scores. Older patients, aware of cancer diagnosis, poor performance status, high pain score, symptom distress, and psychological distress were associated with a poor QOL. These results are consistent with those of a previous review that was primarily focused on hospital-based PC services and examined similar QOL contexts. According to this analysis, cancer patients with PC in developing nations were more likely to score higher in QOL/QOL domains if they were older (>65 years), married or had ever married, had a high educational level, utilized complementary and alternative medicine (CAM), and engaged in spiritual or religious activities. However, this assessment was constrained because it just included research from underdeveloped nations [55].

A different review focused on a comparable QOL scenario, although it was exclusive to non-PC, Asian, and female breast cancer survivors. According to this review, individuals with breast cancer experience lower health-related quality of life (HRQOL), especially if they also have additional comorbidities, are receiving chemotherapy, have less social support, and have more unmet needs. Patients' HRQOL may be enhanced by providing them with the right social support and attending to their needs [56]. Our review highlighted the role of various sociodemographic factors like age, gender, and marital status that determined the QOL outcomes in HBPC. Older age was associated with poor QOL in our review whereas, in contrast, some studies reported younger patients with poor QOL [57]. Factors like being married showed better QOL outcomes in our review whereas some studies reported lower QOL scores for them in terms of social/family well-being [58].

Various patient-related determinants such as health factors like poor performance status and psychological distress as well as symptom-related factors like high pain intensity and symptom distress negatively impacted the QOL in HBPC settings in our review. Whereas patient factors like lack of disease awareness resulted in better QOL outcomes. However, there were some inconsistent findings regarding diagnosis awareness as some studies reported contrasting findings that patients' acceptance following their diagnosis might positively influence their QOL [59]. Our results imply that spirituality has a beneficial impact on cancer patients' capacity to cope with psychological distress. According to a meta-analysis, spirituality/religiosity-based therapies improved anxiety,

and stress levels, reduced alcohol consumption, and delayed the onset of depression in industrialized nations [60]. One longitudinal American study found that spirituality and religiosity are cost-effective, help patients find meaning in their suffering, and provide them with hope [61]. Thus, healthcare providers must acknowledge the spiritual and religious requirements of cancer patients in HBPC settings.

Our review reported satisfaction with the care provided during HBPC resulted in better scores in QOL/QOL domains. Similar findings were reported by a study that stated that overall satisfaction was high with better QOL scores, but specific reporting questions revealed many areas for improvement in hospital-based PC services [62].

Our review reported that better QOL/QOL domain scores were associated with patients who preferred home as a place of death. Similar findings were observed in a study, which reported that although home death is sometimes considered a potential indicator of end-of-life/palliative care quality, some factors associated with an increased likelihood of home versus hospital death included multidisciplinary home palliative care, preference for home death, early referral to palliative care, the caregiver's coping skills, etc. [45].

Limitations

It is important to acknowledge that this review has certain limitations. First off, as the review was restricted to works written in English, we might have overlooked pertinent studies written in other languages. It is important to interpret the results with caution because more than three-quarters of the articles received a moderate to low-quality rating score. The comparability of the included research is limited by the various forms of QOL questionnaires. Because different studies used different statistical analyses, we were unable to perform a meta-analysis to determine the degree of relationship. Some findings may be inconsistent and also discordance results observed in certain determinants because different patient selection criteria were used in the included studies. The majority of research used convenience samples and small sample sizes (less than 300), which makes it challenging to generalize the findings.

In conclusion, the sociodemographic (age, gender, and marital status) of cancer patients worldwide, as well as factors related to their health (disease awareness, performance status, psychological distress), home care (satisfaction with care, preferred place of death), cultural perspectives (spirituality), and symptoms (pain intensity, symptom distress), were important determinants of QOL/QOL domains scores in HBPC. Hence, every nation should explore and identify the requirements of its advanced cancer patients and put into practice locally tailored strategies to adopt HBPC more effectively. Stakeholders may use our narrative review as a reference to determine which factors should be prioritized.

Author Contribution Statement

KAK proposed the initial concept idea, and conceived,

and designed the systematic review protocol. KAK, AKR, KSB, and VSB designed search strategies. KAK, AKR, NHM, and SGK undertook the searches and retrieved articles. MY, KAK, VSB, and AKR performed the study selection, data extraction, and study quality assessment. KAK wrote the first draft of the manuscript. All authors discussed, advised, and revised the manuscript. All authors read and accepted the final version.

Acknowledgements

Ethical Declaration

This study reported only already published data. We had no direct access to the original data used in the included studies for the review. Therefore, no ethical approval was needed.

Data Availability

The data and material of this systematic review will be made available to the public upon request.

Study Registration

We registered our systematic review with PROSPERO database with the study registration no. CRD42024529787.

Conflict of Interest

None

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