

REVIEW

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Systematic Review and Meta-Synthesis about Patients with Hematological Malignancy and Palliative Care

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Abstract

Objective: The current study aims to review, appraise, and synthesize the available studies and recommend the significant clinical implications for healthcare professionals to understand the existing findings of palliative care experience among patients with hematology malignancy. **Methods:** After excluding the registered or ongoing systematic reviews in the PROSPERO database regarding the lived experience of palliative care among patients with HM, our systematic review and meta-analysis protocol was registered in PROSPERO [CRD42021270311]. A search for published articles in English between January 2000 and December 2020 was conducted among different electronic databases using PRISMA guidelines 2020. Meta-synthesis was accomplished using the JBI meta-aggregation method to synthesize the findings. The implemented approach involved all qualitative research and mixed-method studies that included a qualitative part. **Results:** This review contained eight studies which led to 25 codes and seven categories. Finally, three synthesized themes were developed: (1) Approaching the end of life among patients with Hematology Malignancy, (2) submission and surrender of patients with Hematology Malignancy during their terminal stage, and (3) Entrance to the palliative care world. Therefore, realizing the importance of palliative care services to patients with Hematology Malignancy by providing evidence-based education and timely referral is crucial. **Conclusion:** There was a substantial increase in the HMs rate with late referral to palliative care services. The results of this review may draw attention to some issues reported by patients with Hematology Malignancy. Scaling up palliative care services for those patients is essential to minimize end-of-life suffering and the long-term impact of inadequate palliative care for patients with Hematology Malignancy.

Keywords: Hematology malignancy- patients- qualitative research- systematic review- palliative care

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Introduction

Hematological Malignancies (HMs) are unique and diverse forms of hematopoietic and lymphoid malignancies that affect the blood, lymph node, and bone marrow. Worldwide, the estimated number of newly diagnosed patients with HMs in 2020 was about 1.3 million, and around 0.7 million were dead from HM (Siegel et al., 2022; Sung et al., 2021). Patients with HMs complain of several symptoms that are associated with a high level of burden, and distress (Richter et al., 2021; Senf et al., 2020), in addition to ongoing unmet needs relating to their illness which lead to the inability to achieve satisfying psychological well-being (Pereira et al., 2020; Stevenson et al., 2020; Zomerdijk et al., 2021). Previous studies were conducted to explore their experience with illness trajectory revealed that many patients with HMs experienced physical impacts such as fatigue, impaired physical functioning, delirium, drowsiness, stomatitis, diarrhea, in addition to infection, fever, dyspnea, tiredness,

and bleeding (Ramsenthaler et al., 2019; Shaulov et al., 2019; Wang et al., 2020). At the end of life, most patients with HM receive aggressive treatments such as administering chemotherapy, hospital and intensive care unit admissions, and other invasive treatments and procedures (Cruz et al., 2017; Verhoef et al., 2020).

Palliative care (PC) focuses on advice about therapeutic decisions, symptoms management, and family support. However, due to the unexpected nature of HMs, a delay in suitable transition to PC could occur between the initial, late, and terminal phases (D. Moreno-Alonso et al., 2018). The national PC standards (2018) described that referral to PC services is appropriate when the needs of the patients exceed the available resources for those patients. Many studies were conducted to investigate the impact of PC services on patients' well-being either in acute care settings or out-patient settings/ at home. Some studies agree that PC offers comfort care for patients with cancer and receiving PC interventions.

Patients with an HM have a short life expectancy,

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and providing PC services occurs in a short time (Adersen, 2017; Deborah Moreno-Alonso et al., 2018). For that, PC teams faced several challenges in building rapport relationships with patients and their families and discussing the palliative and end-of-life care services (Gao et al., 2020), and PC provided for patients with HM was mainly delayed and less frequent when compared with solid cancer (Verhoef et al., 2020). Accordingly, determining the potential for cure and when the patients could enter the terminal stage of HM was difficult (Odejide et al., 2017; Ruiz et al., 2018). The delayed referral of HMs patients could be associated with the cancer prognosis, different approaches for treatment, benefit from chemotherapy, and 'patients' preference to manage their aspect of care (Oechsle, 2019; Ruiz et al., 2018).

Many studies have explored oncology patients' experiences of PC from many points of view; however, preliminary studies are conducted to explore the experience of PC among patients with HMs to institute a comprehensive understanding of their distinctive experiences. In addition, not too much consideration has been taken on the aspect of PC experience among patients with HM, and most of them referred to PC at a late time when compared with other types of cancer (Black et al., 2018; Flidner et al., 2019; Laursen et al., 2019; Vasileiou et al., 2020). Therefore, the current systematic review aims to assess, evaluate, and synthesize the available studies and recommend some clinical implications for healthcare providers to understand the current findings on the experience of palliative care among patients with HM.

Materials and Methods

This review was considered as a qualitative approach according to guidelines of the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for qualitative research (Lockwood et al., 2015). This protocol was registered in the PROSPERO database (CRD42021270311).

Study source and search

An electronic review in MEDLINE, CINAHL, and PubMed databases was conducted for all published studies relating to providing palliative care services for patients with HM. A manual search was performed for used references in articles to obtain additional relevant sources.

The exploration for relevant studies was performed on July 25, 2020, based on standard systematic review guidelines by Cochrane collaboration (<https://www.cochrane.org>) and Campbell Collaboration (<https://www.campbellcollaboration.org>). A search for published articles in English between January 2000 and December 2020 was conducted among different electronic databases using PRISMA guidelines 2020. Studies that were not published in English were excluded. The search strategy in all databases was performed using the following search terms: "Hematological Malignancy" (blood cancers OR Leukemia OR lymphoma OR myeloma OR oncology OR cancer OR hematological cancer), AND "Palliative Care" (palliative care OR supportive care OR end of life care needs), AND "Qualitative Research" (qualitative study OR grounded theory OR phenomenology OR lived

experience); AND "Patients." For further details about the search strategy, refer to Appendix (1).

Inclusion and exclusion criteria

Population

This review includes all HM patients referred to palliative care services. Palliative care is defined as an approach of care that is provided for patients who were diagnosed with a life-threatening illness and the available therapeutic options become limited; thus, palliative care aims to alleviate patients' suffering and manage their symptoms in order to improve their quality of life (World Health Organization, 2012). The target population was the HM patients who reached the terminal stage of cancer with limited therapeutic options and were referred to palliative care services. Respondents should be adults (aged 18 years and above), able to provide informed consent, and verbally communicate their experiences. Qualitative studies that described the experience of patients and caregivers together were also integrated.

Phenomena of interest

The focus of this study could include patients' experience with HM, challenges, perception, feelings, decision-making process, and utilizing coping approach.

Context

The context of this study was the entire experience of PC among patients with HM in the hospital or at home in different PC settings.

Design

The implemented approach was qualitatively based and involved all qualitative research approaches. Mixed method studies, including the qualitative part, were also integrated into this review.

Exclusion criteria

The exclusion criteria for studies were: duplicate papers, unavailable in full-text format; reviews and quantitative studies; including pediatric oncology or solid cancer patients as a sample; and studies were not available in the English language. Qualitative studies that described the experience of patients and healthcare professionals together were excluded.

Data extraction

A tool developed for qualitative data extraction by the Joanna Briggs Institute (JBI) was applied in this review (Appendix 2). The criteria for data extraction were limited to precise author details, country, year of publication, sample, sample size, settings, purpose, data collection method, key findings, and conclusion. When a mixed-method study was included, the qualitative part was only considered. Also, the evidence that explored patients' experience with HM was included.

Assess the quality of included studies

The JBI Critical Appraisal Checklist for Qualitative Research (Munn et al., 2014) was implemented to evaluate the quality of each included study in this review

(Appendix 3). Two researchers evaluated the included studies independently, and if disagreements occurred, a discussion with a third examiner was performed to achieve a consensus.

Data synthesis

In this review, the JBI meta-aggregation method was utilized for synthesizing the findings (Lockwood et al., 2015). Meta-synthesis includes three steps; the first one starts with the extraction of the entire study from all included evidence, then creating categories, then extracting one or more themes from two categories or more. Two authors have performed the process separately to attain the reliability of the results.

Results

Study inclusion

The study selection process was presented in the PRISMA flow diagram (Figure 1). Overall, eight studies were chosen for this systematic review after appraising the quality of included studies.

Methodological quality

According to the JBI critical appraisal checklist, the finding of the quality assessment for the included studies was moderate to strong. Four studies were rated high score (9/10 score), and the remaining four rated moderate (7–8/10). For further details, refer to Table 1. The included evidence in this review was of unique quality, which

Characteristics of included studies

The current review involved eight qualitative papers available between 2002 and 2017 in three countries. The number of participants in the included studies extended from 1 to 50, and the total sample of all studies was 116 participants. Any qualitative study was utilized to explore patients' experience with HM along with their perceptions and attitudes toward PC throughout the illness trajectory. These characteristics are presented in Table 2.

Findings of the review

The finding of the eight studies was summarized in 25 codes and seven categories. Finally, three synthesized themes were extracted, see Table 3:

1. Approaching the end of life among patients with HM
2. Submission and surrender of patients with HM during their terminal stage.
3. Entrance to the palliative care world.

Synthesized finding 1: Approaching end of life among patients with HM

When patients with HM were reaching the terminal stage, treatment options became limited. In this stage, patients experience a stressful journey that begins with physical and psychological suffering, in addition to receiving aggressive interventions in the last days of their life. Also, they began to deteriorate and were more likely to die nearly. Subsequently, they are approaching the end

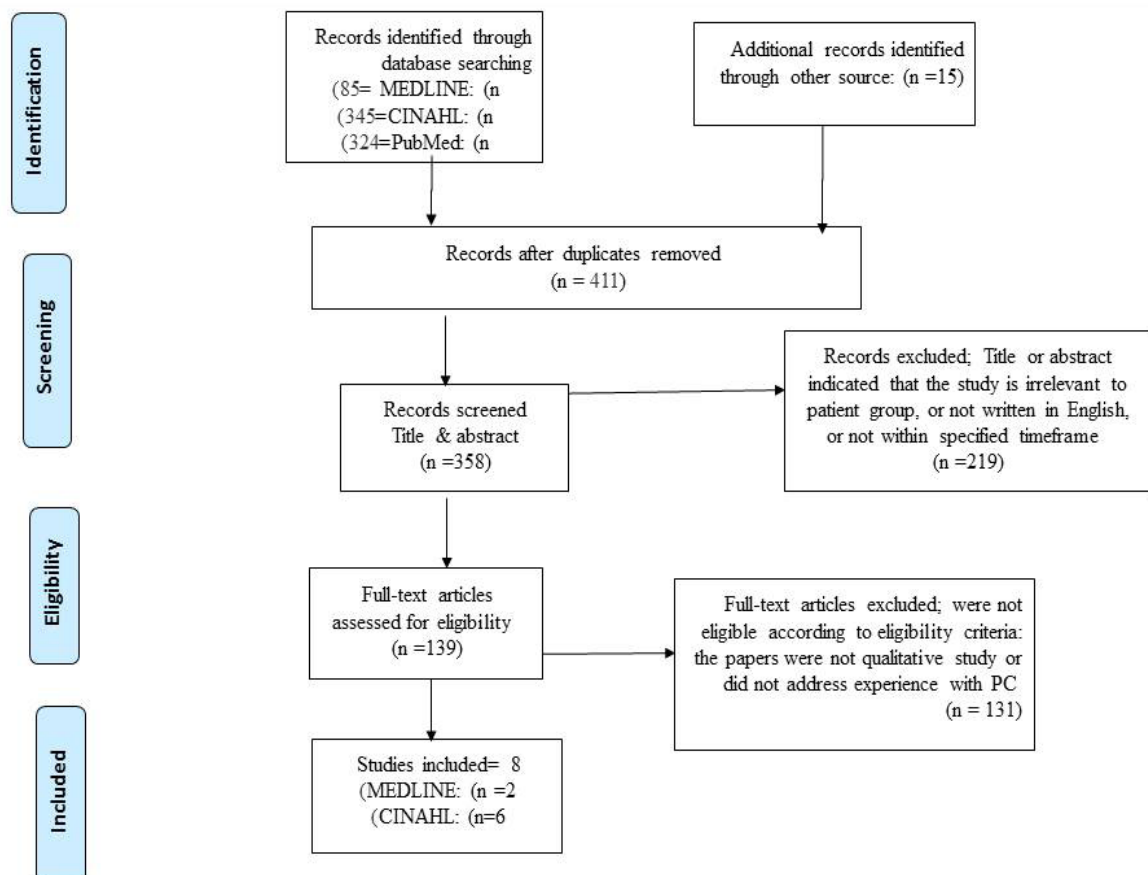


Figure 1. Flow Diagram of the Systematic Search Strategy

Table 1. Critical Appraisal of Studies Using the Consolidated Criteria for Reporting Qualitative Research (COREQ) Qualitative Appraisal Tool

| Study | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Total (%) |
|--------------------------|----|-----|-----|-----|-----|----|-----|-----|-----|-----|-----------|
| McGrath, 2013 | NA | Y | Y | Y | Y | Y | Y | Y | Y | Y | 90 |
| Nightingale et al., 2011 | NA | Y | Y | Y | Y | U | Y | Y | Y | Y | 80 |
| McGrath & Joske, 2002 | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 90 |
| McGrath & Clarke, 2003 | Y | Y | Y | Y | Y | U | Y | Y | Y | Y | 90 |
| McGrath, 2002a | NA | Y | Y | Y | Y | U | Y | Y | Y | Y | 80 |
| McGrath, 2002b | Y | Y | Y | Y | Y | U | Y | Y | Y | Y | 90 |
| McGrath, 2002c | U | Y | Y | Y | Y | U | Y | Y | Y | Y | 80 |
| Boucher et al., 2018 | NA | Y | Y | Y | Y | U | Y | Y | Y | Y | 80 |
| Total (%) | 38 | 100 | 100 | 100 | 100 | 13 | 100 | 100 | 100 | 100 | |

Note, Y, yes; N, no; NA, not applicable; U, unclear

of their life very quickly.

Category 1: Stressful experience from the time of diagnosis until the last days

From the moment of the diagnosis, the physical and psychological status of HM patients changed frequently. Many patients had no idea about the disease and the treatment that might take and could only wait. They experienced a shock status from being informed about the condition or decline. An example that reflects patients' shock and depression is presented in the next quotation,

"I just walked out in a state of shock; I couldn't open my mouth. I just walked out as if the whole world had stopped. Tears were running down my face ...I didn't have a clue where I was going"

Some patients described their distress resulting from stress and depression after the diagnosis. Examples of descriptions that reflect post-traumatic stress and frustration among patients are as follows,

"When they actually put a name on what I was suffering, saying you are suffering from post-traumatic stress, a light went on to say I am not crazy; there is a name for it."

"I want to keep a clean house, but I'm just too tired, and it's very frustrating."

"I was sort of shut down. I didn't really say much. Because what I was thinking, it was all pretty dark stuff"

Other patients reported a state of uncertainty in terms of the plan of treatment and the prognosis of the illness; these points are reflected in the following statement

"... there's a lot of uncertainty, and it's not just like getting through a week, and then everything is okay, that uncertainty is going to be there for months, if not years...."

Category 2: Aggressive treatment at the terminal stage

Some patients reported that they received treatment, but it affected them negatively. The following statement reflects patients' expressions about how chemotherapy affected them.

"The chemo was horrendous, and I wish I had just died. I wished that I had been hit by a truck."

"Initially, they wanted to see if the treatment would kill me or whether I'd survive that chemo."

Some terminally ill patients with HM whose health

status deteriorated reported that their patients were admitted to ICU. An example of family caregiver expression was on as the following:

"The ICU experience was just awful."

"It was horrible. In all due respect, I thought the ICU unit was terrible."

Some family members described how aggressive interventions were provided for their relatives in ICU. See the following statements

"They put [the patient] out with drugs to make [the patient] unconscious and paralyzed, so [the patient] could not move. Hopefully, [the patient] didn't know what they were up to."

From the family caregivers' perspective, some family members described how inadequate treatment options affected the patient and them. Notice the following quotation.

"(The patient) had to have a second protocol because the first one didn't work... didn't go into remission, so we were very distressed about it."

Another family caregiver described the care provided for their relatives with HMs as experimentation. See the following description.

"It was only new to them (the doctors) too. So I really felt, no traces of blame, that (the patient) was just an experiment."

Category 3: Patients approaching the end of life quickly

Many patients with HM disease suffer from rapid physical deterioration at their terminal stage. The dramatic changes and worsening in patients' health status occurred within a short period; see the following patients' expressions that reflect how their health status worsened quickly.

"He (the patient) went for some blood tests, and they told us that it had changed to Leukemia, and it had jumped the tracks we had been told."

"But I don't know that people know it will happen that quickly, but it does."

One of the patients did not wish to be transferred to ICU after deteriorating rapidly in the last few days. See the following statement.

"Am I going to be put in ICU?" The nurse said, "No, we will look after you here." The patient did ask about

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Table 2. Characteristics of Included Studies

| First author, country, year | Design | Purpose of study | Data collection method | Sample, settings, sample size | Key findings | Conclusion |
|----------------------------------|-------------------------------|---|---|--|--|---|
| McGrath et al., Australia, 2013 | A qualitative design | To explore the survivorship experience of adult patients diagnosed with a hematological malignancy | Open-ended interviews and focus group | "HM patients and a survivor group Cancer foundation N=50 (n = 26 male; n = 24 female)" | "Participants who know enough about the benefits of palliative care are more liable to received palliative care at their E-O-L. Many patients reported the problems in referral time to the palliative care services. Patients aware that they facing the death." | There is enhancement in the hematology patients' awareness about the important of palliative care. Also, there is a great role for the social worker to offer more knowledge about PC services. |
| Nightingale et al., UK, 2011 | Case report | To identify key EOL care issues | Open-ended interview | "HM patient HMT+PCU units N=1 (acute myeloid leukaemia)" | "Demonstrates the relevance of PC team involvement Importance of discussing issues around prognosis and clinical transition; consider sequelae from curative treatment and interventions at EOL * discussion about place of death and community care" | "Initiating EOL care should be offered in patients with HM. There is a need for improved coordination, contact, and referral process between interdisciplinary team members as well as with other hospital or community resources to Offer comprehensive care of patients with HM especially in end of life." |
| McGrath et al., Australia, 2002a | Case report | To address the aspects of PC among patients face dying in HM | A phenomenological approach- open-ended interview | "HM patient Public Health Department * N=1 (Mantle cell lymphoma)" | Many factors were noted as facilitator for referral to PC in appropriate time (knowledge of hospice and palliative care; appreciated honest information; rapidly changing the patient condition; fast disease progress into terminal stage; strong acceptance of death; direct referral to PC. Many factors facilitating dying at home (offered dying at home as feasible option; it is patients wish as career understanding; career supporting patients in this option; offering of adequate support and proactive knowledge for patients. | Positive experience in for a patient with a HM at the terminal stage. Also, this study give insight on how to address the neglected palliative needs of patient with HM. |
| McGrath et al., Australia, 2003 | Phenomenological design | To document experience of survivors of HM with spiritual issues | Open-ended interview | "HM survivors hospital at Leukemia Foundation of Queensland N=12 (n=8 male, n=4 female)" | "Talk about spiritual issues is challenging but helpful. Patients desire to protect family. Self-autonomy to share the experience with others Close the illness experience and need time to talk about other things in life" | The study gives insight for patients with HM that hope and expectation during their experience is important to deal with this illness. |
| McGrath et al., Australia, 2002b | Phenomenological approach | To analyze the experiences of hospice/palliative care among individuals with HM and their families | Open-ended interview | "HM patients and their families One of metropolitan hospitals N=10" | "Feeling shocked when they hear about their illness or relapse Knowing their terminal status but they hope to cure and to have a positive attitude Feeling of experimentation. Rapid deterioration No referrals to PC system" | Lack of palliative care provided for patients being treated for HM |
| McGrath et al., Australia, 2002 | phenomenological approach | To analyze the experience of patients with HM during palliative care treatment at end of life | open-ended interview | "HM patients and their families One of metropolitan hospitals N=10" | "High-technology curative treatments are used among HM patient at EOL that does not acknowledge dying and PC Lack of PC referrals Patients are aware that the patient is dying. understand the prognosis and desire to die at home" | Many patients' insights are addressed in the context of exploration the experience of HM patients with treatment during the last stage. |
| McGrath et al., Australia, 2002c | Phenomenological approach | To analyze the experience of patients with HM with palliative/hospice care at the terminal stage | Open-ended interview | "HM patients and their families one of metropolitan hospitals N=10" | "Death scene at ICU in which high technological treatments are used No referral to PC" | "Patients with HM and their families have received Limited concentration with regard to the offering palliative care." |
| "Boucher et al., England, 2017" | Descriptive qualitative study | To understand opportunities for palliative care interventions in patients with acute myeloid leukemia | Semi-structure interview | "High-risk patients with acute myeloid leukemia. Inpatient HM unit 22 patients (n= 10 male, n= 12 female)" | "Patient noted physical and psychological issues Uncertainty regarding their prognosis, and their sources of support. Some challenges reported by patients included feelings of helplessness/hopelessness, activity restriction, fatigue, fevers, and ambiguity regarding management decision-making" | AML patients countenance substantial issues related to physical symptoms, psychological distress, and uncertainty regarding their prognosis |

Note. EOL, End of life; AML, Acute myeloid leukemia; HMT, Hematologic Malignancy & Transplantation unit; PCU, Progressive Care Unit

Table 3. Themes and Subthemes Developed from Selected Studies

| Synthesized finding 1: Approaching end of life among patients with HM | | |
|---|--|--|
| Stressful experience from the time of diagnosis until the last days | Aggressive treatment at the terminal stage | Patients approaching end of life quickly |
| Shock | In ICU little grain of hope | Happen quickly |
| Suffering | Experimentation | Jumped the tracks |
| Tiredness | Chemo destroyed my body | Saw the end of the story |
| Uncertainty | Drug induced paralyze | Sudden decline |
| A lot of time without usefulness | | |
| Synthesized finding 2: Submission and surrender of patients with HM during their terminal stage | | |
| Accepting the death | Struggling for survival | Home is the preferred place |
| Acknowledgment of the truth | Determination and perseverance | Return to home |
| Patient aware how illness is dangerous | Coping with illness | Comfort with home Surroundings |
| Synthesized finding 3: Entrance of palliative care world | | |
| Missed opportunity | Glimmer of hope | |
| Nothing suggested about referral to PC | I know a bite about PC | |
| Know about PC in late | Happy to know | |

the Tuesday; she died on Saturday night.”

Synthesized finding 2: submission and surrender of patients with HM during their terminal stage

Once the patients’ health declined and the availability of treatment options was limited, patients and their families felt like they were nearing the end of life for their loved ones. Acknowledge the imminent death was reported by many oncology patients and their families. The deterioration of the patient’s condition occurred unexpectedly; however, patients still have hoped to cure or extend their life. Most participants who were approaching the end of life and accepted that they were dying; are preferred home as the best place to wait until the death occurred.

Category 1: accepting the death

It is significant to know that most patients don’t think about the risk of dying only, but they have already reported that they are in front of the death; see the following description, which reflects the patients acknowledged the death.

“I accepted that there was nothing anyone could do, I am going to die, so I wasn’t nervous about what I do now.”

“We always said whatever we were getting was a bonus from the point that he was diagnosed.”

Also, many family caregivers of patients with HM reported their perception of the patient dying and how the patients react to it. See the following statements that reflect the perception of family members about the death of their loved ones.

“[The patient] was aware of how dangerous it was and all that sort of thing.” *“[The patient] faced it quite strongly by going and taking out a will.”*

“[The doctor] told me right from the start that [the patient] didn’t have much chance. He told me in the first week that [the patient] had an 18% chance of survival.”

Category 2: struggling for survival

Despite patients at their terminal stage, they still have

a hope to cure. See the following statements that reflect the patient and family hope to survive.

“What are my expectations for the future? Well, I’d like to know that this is cured, if not I’d like to have at least 5 or 6 more years of life ahead of me”

“I couldn’t afford to feel down. I was trying to be positive, and with my medical situation, there was an improvement.”

Additionally, other patients and families reported that they have positive attitudes toward living for a long time as much as possible; see the following expressions:

“Just stay positive...move forward.”

“We’ve moved on from cancer. It was a stage in life. We don’t dwell on the fact that I might only live to 75 instead of 85 or 93 like dad did or something. All we want to do is make sure we are physically able to do what we want to do and look at doing that for as long as possible.”

Category 3: Home is the preferred place

Family caregivers reported the preferred place of death for their loved ones. Most patients preferred home as the best place to die. See the following description of the family members that reflects the patient preference of death place.

“As it were on, [the patient] just wanted to go home.”

“He [the patient] desired to die at home. I said about dying, what do you want to do and he said I would like, firstly, to be free of pain, secondly the quality of life, and thirdly, to die at home.”

Others reported how their patients were comfortable with the home environment and surround

“It would have been beneficial because you wouldn’t have to worry about not losing it in front of people and stuff. You would have had more privacy.”

“As soon as [the patient] got home, [the patient] started eating.”

Synthesized finding 3: Transition of patients with HM to palliative care

HM patients who reach the terminal stage need accurate

information about PC, which is considered helpful for patients and families. Some patients acknowledged that the referral to PC depends on their submission and knowledge. Incongruent with short life expectancy, the timely referral of patients with HM to PC services is significant (Adersen et al., 2017; LeBlanc and El-Jawahri, 2015; Deborah Moreno-Alonso et al., 2018).

Category 1: The missed opportunity

The impact of the rapid decline of the patient's condition and due to disease trajectory with a lack of prediction for the time of deterioration, all these issues affect the time of referral to PC. Some patients with HM and their families talk about the referral to PC services; they reported that the referral to PC services was delayed and occurred in the last time; see the following statements:

"We got involved with Silver Chain even though we didn't need it at this stage, and they just said to get on their books. So everything was in place so that everything would flow smoothly when we needed it".

"Yeah, I would never have heard about it beforehand, no. At the time, that was just not an option for us."

Other patients and families reported that referral to PC services was not introduced for them at all; see the following statements:

"At no point did anyone come to me and turn around and say, OKAY, this is what you can do...Nobody spoke to me about it [hospice]; nobody tried to speak to me about it."

"No, they didn't suggest anything like (palliative care or hospice). The hospital was going to keep (the patient) there."

"No, we didn't even know it [hospice] existed, to be really honest...It could have been so different, and it could have been a better experience."

Category 2: Glimmer of hope

Patients with HM who were confidently approaching palliative care were the only ones who were fortunate to receive adequate knowledge about the benefits of palliative care. Some patients addressed that they get informed about PC and the treatment options, see the expression that reflects their voice:

"We wanted to know, so we always asked the questions, and they were always honest with us. We were much happier knowing what was going on because at least that way you know what is happening; you are not in the dark."

"It was something I felt ...I could do myself. I felt I knew as much as anybody could tell me."

Some family caregivers also described that they get knowledge about PC and their relatives. The following quotations reflect that.

"(The doctor) told the truth so that you can prepare."

"Find, (the patient) was aware of how dangerous it was and all that sort of thing."

While other patients and families reported that they wish to get knowledge about PC that could affect the decision-making of their treatment, see the following examples:

"If they would have come earlier, I could have coped with that and met [the patient's] wish to go home, but

Palliative Care among Patients with Hematological Malignancies because they left it too long, nothing would have helped."

"If they could have said to me—probably a month earlier—look, we can't see any hope, sorry, we have done all we can, let [the patient] have quality time, I would have said thank you and gone home. But we just hung in there."

Some patients reported receiving information early about PC when they were in healthy or better health status is better; see the following statement.

"I think to know while you were in a better state of mind that information might be better now than you know, six months down the track so you can start to plan and start to feel sure that your loved ones are taken care of."

Discussion

This systematic review intended to appraise qualitative studies that understand the lived experience of patients with HM during their journey in PC units. According to the included studies, three merged themes were recognized. The results show that the evidence remains clear about the inadequate providence of PC services from the perspective of patients with HM and family caregivers.

Previous studies indicate that patients with HM have numerous physical symptoms, distress, and psychological burdens similar to advanced solid tumors (Ramsenthaler et al., 2019; Shaulov et al., 2019; Wang et al., 2020). Besides, patients with HM have a short life expectancy and deteriorate suddenly more than other oncology patients (Deborah Moreno-Alonso et al., 2018). Subsequently, many patients with HM reach the terminal stage quickly when the treatment options become limited (McCaughan et al., 2018). Therefore, patients with HM at the terminal stage experience a stressful journey that began with uncertainty, shock, and suffering. In addition to the feeling of depression, many of them experienced anxiety, fatigue, fear, and emotional distress. Many physical and psychological symptoms are frequently reported in the included studies (Boucher et al., 2018; McGrath, 2002b, 2002c).

Patients with HM at the terminal stage mostly received aggressive treatments such as administering chemotherapy, hospital and ICU admissions, in addition to other invasive treatments and procedures (Verhoef et al., 2020). Receiving aggressive interventions in the last days of life for this group of patients was documented in the literature (McGrath, 2002b, 2002c; Ramsenthaler et al., 2019). Despite that, patients with HM are more likely to die near the end of their life.

Submission and surrender of patients with HM during their terminal stage was another significant theme synthesized from the review. Whenever the treatment options become not beneficial and the patients' health status deteriorates, the patients and their families feel like they are nearing the end of life for their loved ones. Accepting of patient and family the imminent death was stated in the most reviewed studies (Boucher et al., 2018; McGrath, 2002a, 2002c; McGrath, 2013; McGrath and Clarke, 2003; McGrath and Joske, 2002). As patients believe they are dying, they start preparing for death as written the advance directive and considers patient wishes with complete surrender. Regarding preferences, some

patients with HM prefer the hospital as a suitable area to die in than home (McCaughan et al., 2019). However, some patients feeling of surrender to death. Two studies revealed that patients were approaching the end of life and accepted that they were dying, and they preferred home as the suitable place to wait until the death occurred (McGrath, 2002c; McGrath and Joske, 2002; Nightingale et al., 2011). Each disease has a distinctive illness trajectory; thus, the submission and surrender of patients with HM were identified. Due to the rapid decline of health status and limited treatment options in patients with HM at the final stage, their lived experiences and needs were perceived differently than patients with other diseases.

Due to unexpected deterioration in the health status of HM patients, some still have hope to cure or extend their life despite their surrender to death. Hope predominated among cancer patients, and it was originally inferred from patients' faith and spiritual power (Baczewska et al., 2019; Ozen et al., 2020). Insistence and glimmer hope to survive were frequently reported in the literature (Boucher et al., 2018; McGrath, 2002a, 2002c; McGrath, 2013; McGrath and Clarke, 2003; McGrath and Joske, 2002). Patient submission and surrender, faith, and hope to survive in peace; can be utilized as helpful influences to communicate with them and their families about the PC.

Introducing PC to cancer patients and non-cancer patients is significant (Hui and Bruera, 2020). The time of offering PC services as early as possible for patients with HM at the terminal stage is significant. Some of the reviewed literature revealed that the discussion of the PC option happened belatedly (McGrath, 2013; McGrath and Joske, 2002; Nightingale et al., 2011), while other studies reported that no communication about PC services has occurred with HM patients or their families (McGrath, 2002a, 2002c). Many patients, families, and healthcare providers highlighted the importance of timely referral of patients with HM to PC services congruent with short life expectancy (Hui and Bruera, 2020; D. Moreno-Alonso et al., 2018). In this regard, providing individualized information to the HM patient and family members about the disease trajectory, management options with adverse effects, and discussing the PC options early is crucial (Hui and Bruera, 2020; Ruiz et al., 2018). In this review, many of the terminally-ill patients with HM acknowledged that the referral to PC is related to their understanding and the received knowledge about PC services which is helpful for patients as well as their families (McGrath, 2002a, 2002b; McGrath, 2013; McGrath & Clarke, 2003; McGrath and Joske, 2002).

Further qualitative studies should be conducted to explore the lived experience of HM patients after receiving PC services at an appropriate time. First, training and education sessions for healthcare providers, patients with HM, and their family caregivers are essential. Mainly when the patients are at the terminal stage, which will help them offer more best and comfort care. Moreover, written health care material should also be offered and distributed to all patients with HM and their families as a reliable source. Utilizing different sources such as the community health care institutions, social media, telehealth, and the public conference should also be engaged to educate

patients and families about PC services. In addition, the healthcare policymaker should modify some policies associated with caring for patients at the end of life. Also, they have to follow the international models for PC and hospice care among terminally ill patients with HM to improve their lives.

In particular, this review represents an informative image of the experience of HM patients during the disease trajectory by merging eight qualitative studies. It is significant to remind that patients with HM at the terminal stage are approaching the end of life more quickly than others. In addition, they are aware that they are dying despite their assistance to survive. In addition, to provide the best end-of-life care, patients with HM need to be referred to PC early as possible. As the HM illness progress rapidly, the transition of patients to PC services is challenging. Healthcare providers are expected to adapt their care protocol dynamically and supply individualized care for patients with HM and their families.

In conclusion, the patients with HM experienced approaching the end of life quickly at the terminal stage. The rapid deterioration occurred congruently with their submission to imminent death and insistence on hope to survive. However, patients with HM and their family members reported few referrals of the patients to palliative care. Therefore, realizing the importance of PC services to patients with HM by providing evidence-based education and timely referral is important.

Limitations of the review

Like with any research, this review has some limitations. One of them is excluding the influence of authors on the findings and vice-versa in all included evidence. This point alluded to considering the individual bias that affects the quality of included studies, and it reflected a presence of a little individual effect at some stage in the meta-synthesis. Additionally, excluding unavailable articles in the English language could challenge the reliability and transferability of the findings of the review in all socio-cultural contexts.

Implications for clinical practice

The current systematic review precisely recognized the PC experience among patients with HM. It involves patients with HM from diverse environmental and cultural contexts and disease types; therefore, they are close to the end of life, have certain needs, and have difficult transitions to PC sound systematic and prevalent. The insights explored from patients with HM revealed a comprehensive picture of the reasons for the scarce receipt of PC among patients with HM. From these experiences, rapid deterioration with inadequate preparation for patients and families for death and patient surrender for end of life seemed more prevalent than the holistic family-centered approach of palliative care, particularly at the terminal stage and during the dying process.

Author Contribution Statement

Dr. Mohammad Alnaeem; Contribution towards the manuscript: Concepts, design, the definition of

intellectual content, literature search, data acquisition, data analysis, construct of the themes, manuscript preparation, manuscript editing.

Dr. Hala Bawadi; Contribution towards the manuscript: data analysis, theme construction, manuscript editing, manuscript review., manuscript proofreading.

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Conflict of interest

The authors declare NO conflicts of interest.

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