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Family expectations of elderly palliative care: A literature review

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Abstract

Background: It is estimated that 40 million people require palliative care yearly and most of the people live in low and middle-income countries. Palliative care as taking care of the elderly in such a way that suffering is prevented, and relief brought about for both adult and pediatric patients.

Aim: To establish the expectations of family in elderly palliative care

Method: The sources used in this literature review were limited to CINAHL and Google Scholar. The literature review comprised of two databases during the period of 2010 to 2020. In order to insure the objectives were met, the use of critical appraisal was introduced and articles were debunked and methodically examined.

Results: This literature review shows that palliative care integration within primary healthcare can be achieved through building information and communication skills of healthcare providers, engaging and empowering patients to exercise their agency in care decisions, and adequately delineating healthcare providers' roles to ensure staff work within their competencies and training. Educational awareness campaign should be carried to debunk any misconceptions on palliative care and increase its uptake by the elderly.

Conclusion: Training programs for health care providers and palliative and grief care education programs for the public should also be developed. Family members must also have basic knowledge of how to deal with elderly people who have terminal illness and in need of special care.

Keywords/tags (subjects)

Palliative care, nurses' role, family, evidence-based practice, elderly

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1 Introduction

It is estimated that globally 40 million people need palliative care and majority of the people live in poor countries (Jiaqi et al., 2020). Global statistics show that "14% of the world's population is in need of palliative care". In accordance with Jiaqi (2020), limitations on the use of morphine and other drugs used in palliative management has resulted in limited to access to palliative care and pain relief. It is also observed that training deficiencies and general awareness of palliative care in the health profession hinder access to palliative care (Melender et al., 2020). It is projected that the global demand for palliative care will rise rapidly because of emerging and increasing chronic conditions and an ageing population and that access to early palliative care reduces hospitalization and avoids unnecessary usage of health services (WHO,2018).

The World Health Organization (2016) estimates that "on average 50% percent of all deaths are avoidable if there is enhanced access to palliative care". Palliative care is also required by people suffering from acute illness. WHO, further asserts "a significant percentage of adults who need palliative care suffer from chronic diseases such as cardiovascular diseases, cancer, chronic respiratory diseases, AIDS and diabetes. In addition, patients with other conditions such as kidney failure, chronic liver disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies, and drug-resistant tuberculosis are also in need of palliative care. Children may have a high incidence of congenital anomalies and genetic conditions and mortality is highest in the neonatal period" (WHO, 2016).

Globally the population of persons over 60 years was estimated in the year 2020 to be one billion and by the year 2050 the number is expected to rise by four hundred million. This number is projected to rise overtime especially in the middle- and low-income regions. Although the demographic numbers of elderly persons within different regions differ, the developed nations have experienced to have a rapidly greying population (WHO,2022). For instance, WHO (2012) estimates that "by 2050 more than one 25% of the population of the European Region will be aged 65 years and above. In Spain and Italy, over 30% of the population will be above the age of 65". Though disability is decreasing amongst populations of older people in developed countries, the increase in the total numbers means that increased numbers of older people in almost every society will face "the risk of poor health care, dependence and multiple illnesses and disabilities leading to a higher demand for palliative care for this group" (WHO, 2012).

This literature review was aimed at establishing family expectations in elderly palliative care

2 Palliative care

2.1 Defining palliative care

In accordance with the Center for Medicare and Medicaid Services (2014) “palliative care is taking care of people with severe illness which are life threatening at any given stage of live with the aim of enhancing quality of life”. In concurrence the African Palliative Care Associative (2010) asserts that “palliative care improves quality of life of patients and families through early identification, treatment of pain, monitoring and evaluation and taking care of physical, psychological, and spiritual needs of the families and patient”. In unison the Finnish institute for health and welfare (2022), palliative care is aimed to maintain and advance quality of life of both patients and family through improving quality of life. The WHO (2017) is of the view that palliative care is based on five factors, which are relief, cross-professional interaction, relationship, communication, and support for relatives. The organization asserts that palliative care is attainable through early identification, assessment, treatment of pain and problems associated with the disease which may be numerous.

Hawley (2017) view palliative care as “taking care of the elderly in such a way that suffering is prevented, and relief brought about for both adult and pediatric patients as well as their families facing problems associated with life-threatening illness”. In occurrence WHO (2018) describes palliative care as a way of taking care of people with acute sickness with the aim of improving quality of life. Patients and families are affected by challenges related to acute illness. These challenges may be psychological, physical spiritual and socially. Palliative care is aimed at reducing pain, relieving pain and symptoms associated life threatening illness with the aim of improving quality of life and reduce the effects of the sickness (WHO, 2018). The organization is of the view that life is affirmed and dying is regarded as a normal process. During palliative care patients are assisted to live an active life until death and support structures are offered to help the family to manage the patient’s illness and during grief.

“Palliative care improves patient outcomes such as symptom control and quality of life, caregiver outcomes, such as reduced stress and dysfunctional grief” (WHO, 2018). “Palliative care reduces

costs by transferring care from acute care settings to patients' preferred locations such home or in residential hospice" (Bakitas et al., 2015).
"Palliative care involves the inclusion of families and friends as a way of assisting them to cope and adapt to situations associated with acute illness and death of their loved ones" (Espindola et al., 2018). The researchers asserts that palliative care help families to make necessary adjustments during the period when their loved one is ill and to cope during the period of mourning the death of their relative.

The Center for Medicare and Medicaid Services (2014) posits that "palliative care involve the use of ethical principles, inclusive decision making, and advance care planning to detect patients' needs and objectives during their critical stage of life". Various health and social care providers and volunteers such as physicians, nurses and social workers are used as part of the approach to ensure effective and efficient use of palliative care services (Roeland et al., 2016). Care can be provided in various settings such as home, hospitals, and any health-related care settings with limited resources. "Hence this literature review aims at establishing the expectations that families have in elderly people's palliative care" (Kmetec et al., 2020).

2.2 Overview of palliative care

World Health Assembly (2014) resolved that "it was the responsibility of health personnel relieve pain and suffering, whether physical, psychosocial, or spiritual regardless of the condition of the patient or whether the disease or condition can be cured (Resolution WHA67, 2014). The resolution further states that the integration of palliative care into public health care systems is critical for the achievement of Sustainable Development Goal 3.8: universal health coverage. Thus, palliative care is an unconditional medical and ethical requirement that should be accessible to all people in need at all levels of health care systems".

According to the WHO (2018) "specific types and severity of suffering differ based on geopolitical situation, socioeconomic conditions, and culture. People in low and middle-income countries such as Africa may endure less healthy social conditions". In addition, the WHO (2018) states that such people may experience limited access to prevention, diagnosis, and treatment of health problems, to social supports and to specialized services then people in developed countries. Gwyther and Kra-

kauer (2013) highlight that palliative care as not ~~a~~ substitute for prevention, diagnosis, and treatment of common causes of suffering and death such as cancer, drug resistant tuberculosis (TB), cardiovascular disease or mental illness, hence palliative care workers have a responsibility to advocate for these interventions wherever they are not yet accessible. However, the WHO (2018) notes that failure to integrate palliative care with disease prevention, diagnosis and treatment is indefensible (Knaul et al., 2017).

Gwyther et al. (2013) state that palliative care is rarely accessible in less developed countries despite existence of evidence on enormous burden of remediable suffering, and of the efficacy of palliative care to relieve suffering. In concurrence, Knaul (2017) is of the opinion that "inequality in terms of access to palliative care causes disparities in global health care system". According to the WHO (2018), "several barriers have hindered the expansion and growth as well as access to palliative care services. These include; misunderstanding of what palliative care is and its objectives. Additional barriers include: lack of a national palliative care policy, a national palliative care strategic plan and national palliative care clinical guidelines in many countries; lack of basic, intermediate and specialist training programmers in palliative care; lack of staff positions in hospitals and primary care centers that include palliative care as an official responsibility, and that enable clinicians with appropriate training to be paid for practicing palliative care; addiction and diversion (opiophobia), resulting in excessively restrictive opioid prescribing regulations" (WHO, 2018).

The WHO (2016) estimated that in 2017 the world reported 55,945,730 deaths from 195 countries. 73.4% resulted from non-communicable diseases. The Global Atlas (2020) further states that "the global total of all ages, in need of palliative care is 56 840 123 people inclusive of both patients in palliative care and those who are not yet in palliative care" (Knaul et al., 2017) notes that "the need for patients not yet in palliative care was 31 100 719 and was above the number for those in estimated at 25,739,404". According to the Global Atlas (2017) 45.3% of all deaths in 2017 needed palliative care. The organization further estimate that about a third of patients who require palliative care are aged 70 years and above, a quarter are aged between 50-69 and 26% are aged 20-49 and 7% are children aged between 0 and 17 years.

Majority of the 36.5 million people above the age of twenty of decedent and non-decedent palliative care need is related to non-communicable diseases. The Global Atlas (2020) asserts that the overall number of adults in need of palliative care was 52,883,093 and the statics were approximately equal

in terms of gender distribution (with females accounting for half. The organization observed that though cancer accounted for over 70% of adult palliative care, HIV, cerebrovascular diseases, and dementia make a significant contribution.

The Global Atlas (2020) and the WHO (2018) highlighted that 26.8% of adults needing palliative care live in the Western Pacific Region, 20.2% in Africa region, 17.9% in Europe and 17.1% in South East Asia. The Americas and Eastern Mediterranean regions contribute 14.1% and 4.0%, respectively. However, statistics show that the African Region has the highest number of adults in need of palliative care per 100 000 of the adult population, followed by Europe and the Americas regions (Global Atlas, 2020)

2.3 Benefits of palliative care

"Palliative care improves the quality of life of patients and their families faced with problems associated with life-threatening diseases or illness or condition" (WHO, 2018). For Pennbrant et al., (2020) palliative care "reliefs pain through early identification, evaluation and treatment of pain and physical, psychosocial, spiritual and/ or existential nature problems. Palliative care in home settings reduce hospitalizations cost". Zeisel (2013) asserts that "a person-centered design of the care environment result in older people with dementia feeling safe, less anxiety, aggression and apathy". In unison, McAteer et al. (2016) gives better value in patients in palliative care and stops unbearable pain in most instances. Palliative cares improves quality of life characterized by less depression and symptoms. Patients feel more in calmness and are able to avoid risks associated with treatment and hospitalization and have reduced costs with improved utilization of health care resources.

For Fleming, Kelly, and Stillfried (2015) palliative care "creates a good working relationship between the nurse, the older patient and the family". McAteer et al., (2016) further observed that "the merits of palliative care extends to caregivers, family and friends, which demonstrates greater gratification with the quality of care and attention given to patient". The author further contends that "patients who receive palliative care had greater survival rates compared with matched controls who received regular treatment".

2.4 Principles of palliative care

According to the WHO (2018) "principles of palliative care acknowledges that when an elderly patient is approaching the end of life, care is evaluated but it should not be rushed or slowed down and this process is a very normal way of life, the onus is thus on the health care workers to encourage a full life, a befitting farewell". In addition the WHO (2018) further notes that palliative promote equitable access to quality of life during the last stages of the patient's life and assist the patient to have essential health care services. Palliative ensures that home setting care services are adequately resourced through well trained personnel to promote access to high quality care and deliver end of life care. Australian Institute of Health and Welfare (2016) states that "palliative care recognizes, respect dignity, privacy and diversity, including spiritual, cultural diversity, as well as promoting understanding and meeting the needs of ill people". Australian Institute of Health and Welfare (2016) and the WHO (2018) view palliative care as supporting families in bereavement.

2.5 Models of palliative medicine delivery

"Palliative medicine can be delivered in almost all care settings such as inpatient hospital patients, outpatient clinics, assisted living and long-term care facilities and home-based care" (Rosenberg et al., 2013). "These medicines may be provided in person, by video or by telehealth services" (Dionne-Odom, 2015).

Inpatient Palliative Care

"The main sources of palliative medicine include consultative and inpatient units such as a clinician, palliative medicine hospital unit, and interdisciplinary teams" (Bruera and Hui, 2012). In accordance with Finn et al., (2017) palliative care "should encompass consultation from the emergency rooms to intensive care units". Larger hospitals and health care systems with the ability to admit patients for symptom management, support severely distressed families or to manage the imminently dying patient usually have inpatient Palliative Medicine units.

Outpatient Palliative Care

"Most palliative medicine do not have outpatient services as a result of challenges associated implementation and of trained personnel" (Davis et al., 2015) This has impacted negatively on access to palliative care and its effectiveness. The integration of outpatient palliative care medicine into

large oncology systems has the possibility of increase clinician and patient satisfaction. The outpatient Palliative Medicine aims at saving the primary team time by addressing symptom burden, objectives of care conversations, treating the spiritual and physiological thus an active model of care, side of advance care planning and coordination of care. Hui et al., (2016) further states that "the overall outpatient palliative medicine has the ability to deliver care earlier during a serious illness".

Community-Based Palliative Care

"Community-based Palliative Care is a new model of Palliative Medicine that involves both inpatient and outpatient settings to provide care to the serious ill at home or in a long-term care setting" (Finn and Malhotra, 2019). Kamal et al., (2013) espouses that "the aim of CPC is to provide longitudinal care during different stages of sickness and serve as a transition between Palliative Medicine and Hospice" (Bull et al., 2012). Community based care is cheap and can be provided using limited resources to take care of elderly people suffering from life threatening illness such as chronic diseases.

Palliative care pathways

According to Robinson et al. (2015) there "is great potential in improving and standardizing care for patients who have palliative care needs and who are not immediately at the end stage". This approach allows for an individual care plan while accommodating loved ones. It allows for the conversation to take place, the assessment and discuss wishes. "The United Kingdom has attempted to fulfill this notion through having the Gold standard Framework, The Amber Care Bundle and the Liverpool Care Pathway for the Dying" (Robinson et al, 2015).

The Liverpool Care Pathway for the Dying

"The Liverpool Care Pathway (LCP) for the Dying is the most dominant and widely adopted end-of-life care pathway, internationally" (Barclay, 2013). Robinson et, al., (2015) notes that "the LCP was developed in the 1990s in the United Kingdom and was designed to transfer the high standard of palliative care established in hospices to acute hospitals". "The pathway gives direction on the best practices on symptom control, frequent reassessment, appropriate discontinuation of active treatments, and psychological, social, and spiritual care of patients in the last three days of life" (Billings and Block, 2013). According to Neuberger et al. (2013) "the LCP was widely adopted in the United Kingdom and has been translated into different languages and adopted across the world". Robinson et al., (2015) notes that "a recent study in Italy revealed that after implementation of the LCP program in an Italian hospital, no significant difference were noted in the overall quality of care scores

between the LCP wards and the control wards". The authors further states that "more studies on the efficacy of the LCP are being conducted in several other countries".

The Amber care bundle

"The AMBER Care Bundle is a systematic approach to managing the care of hospital patients facing an uncertain recovery and are at risk of dying in the next one to two months" (Barclay, 2013). The bundle pathway encompasses a small number of specific components or actions to improve care.

The Route to Success for End-of-life Care in Care Homes

This pathway was developed in 2010 in the United Kingdom by the National End-of-life Care Programmed (Robinson et al., 2015) and "focuses on addressing the needs of patients in care homes and aims to enhance the quality of care provided at the end of life". "The six-step approach of the Route to Success for End-of-life Care in Care Homes aims to minimize unplanned admissions and ensure residents' wishes and preferences are met wherever possible" (Billings and Block, 2013). "The principles of Route to Success are benchmarked on best practice guidance. The extent to which has the Route to Success for End-of-life Care in Care Homes has impacted positively on the patient care is unclear without robust research evidence" (Robinson et al., 2015).

2.6 Palliative care for older people

"Palliative care is an important public health issue due to population ageing, the increasing number of older people in most societies and insufficient attention to their complex needs", WHO (2012) highlighted that "the proportion of people aged 65 years and above is exponentially increasing in the WHO European Region and in 2009, the age group denoted about 15% of the population of most European Union countries".

In addition, WHO (2012) estimates "that by 2050 more than one 25% of the population of the European Region will be aged 65 years and above. In Spain and Italy, over 30% of the population will be above the age of 65. Though disability is decreasing amongst populations of older people in developed countries, the increase in the total numbers means that increased numbers of older people in almost every society will face the risk of poor health care, dependence and multiple illnesses and disabilities".

“In the past palliative care was offered to people with cancer, but statistics have shown that people aged 85 years and above have greater probability of dying from cardiovascular disease than cancer” (Knaul et. al., 2017). Satisfying needs of older people requires refining and broadening access to palliative care to include people dying from diseases other than cancer and who have multiple illnesses.

“Older people reaching the end of life frequently have multiple debilitating diseases (such as dementia, osteoporosis, and arthritis), and they often do so over longer periods of time (OECD, 2014). For example, 25% people aged 85 years and above have dementia” (Zeisel (2013). These people need palliative care until their last moments.

3 Aim, purpose and the research question

The aim of this study was to establish the expectations of family in elderly palliative care and the purpose is to analyze and describe family members’ needs and expectations during the process of caring for family members in need of palliative care. The research question guiding this literature review was; what are the expectations of family in elderly palliative care.

4 Method

4.1 Literature review

The University of Texas Libraries states that a literature review is a given procedure used in reassessing and collecting data information from evidence based researchers. This is a process of gathering previous results and finding new intel. This is done so as to understand and analysis the new information at hand. This method gives a more forensic research and gives us the ability to map out and organise studies, sub concepts and various research findings (University of Texas Libraries, 2022).

Literature review is a body of academic work written to showcase knowledge gathered on any given topic with its specific question. This body of academic work gives detailed information on both materials evaluated and its current importance. This body of work used the Literature review process by the university of Texas, which is the 7 step process. The research also analysed published and unpublished document related to palliative care and family expectations. The process of finding a suitable topic and question were formulated during the course of the studies. The lecturers helped

with brainstorming and in the process narrowed down the topic to what we had passion for, which is elderly care (University of Texas Libraries, 2022).

We went on to search for journals and papers that were recent maximum shelf life of 10 years (2010 - 2020) and focused on evidence based peer reviewed papers in English in a prescribed time frame so as to keep the work current. The documents also provided a rich source of useful information that was relied upon to make conclusions and draw inferences (O'Brien et al., 2016). In reading we saw unreferenced work, assumptions, bias, religious beliefs exaggerated and popular concepts. All this made evaluating the body work more relatable in finding what's a suitable position. The daunting task of organising the papers, sub concepts and forming suitable patterns for the 6 selected papers. In doing so the thesis was developed and a conclusion was arrived at as the research findings continued. The document was written following the 7 steps in the diagram below , and finally the work was reviewed. The research question is imperative so as to keep us on track, and it gives a boost to further understand a growing need as we live longer and longer (Levac et al., 2010).

7 Steps in the literature review

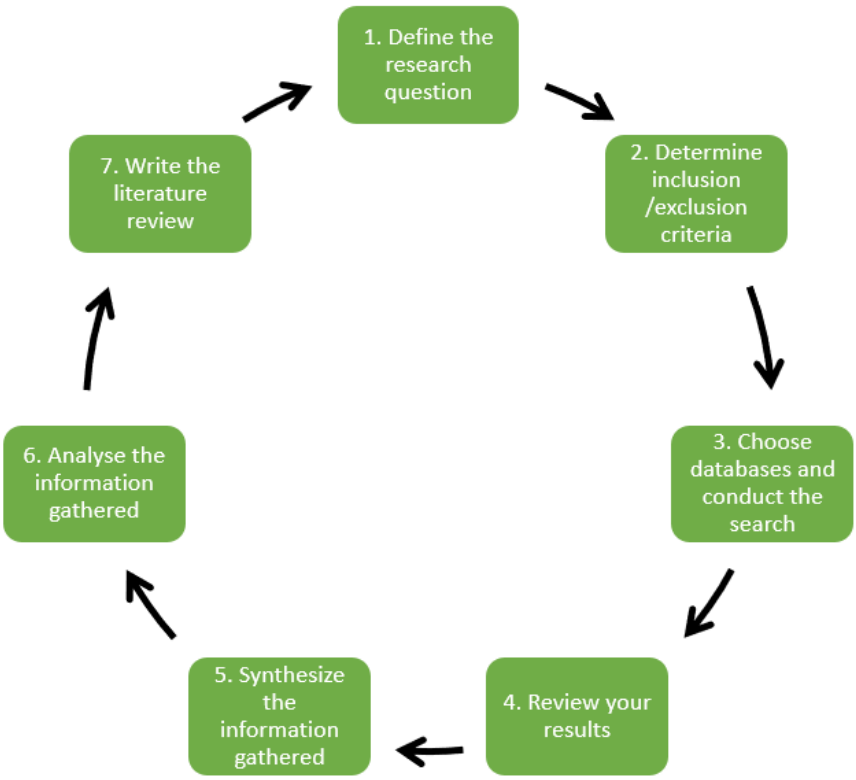

Figure 1. Steps in the Literature Review Process by University of Texas Libraries

4.2 Data search and selection

The two databases that were selected for searching for articles were CINAHL and Google Scholar. The criteria that was given for searching were that the articles had to be original research studies, peer-reviewed, written in English language and were published during the years 2010 to 2022. Figures 2,3 and 4 below shows the PICO-table, Key search words as well as inclusion and exclusion criteria.

On the onset we searched on several databases to see what was on offer, this was in initial stages of the thesis. As winter 2022 dawned on us a research question was arrived at and final search was made CINAHL and Google scholar. CINAHL was the school library database which gave thousands upon thousands of journals and articles. Criteria required is shown in the Prisma flow chart (Figure 3). The criteria was reached by already determining what was to be included and excluded. The rest of the prerequisites were English language, abstract and peer reviewed articles.

PICO TABLE	
Population	Family expectations, palliative care nurses, elderly care
Fact of interest	Evidence based care of palliative care for elderly
Context	Different settings, but mainly care homes
Study	Reviewed studies published between 2010-2022

Table 1. PICO table

KEY SEARCH WORDS
Palliative care and family expectations
AND end of life care
OR end of life

Table 2. Key search words

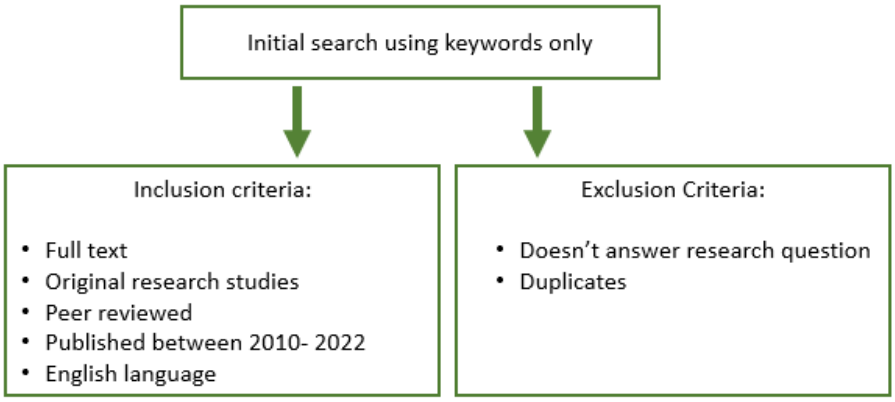

Figure 2. Inclusion and exclusion criteria

Article selection was done by applying the inclusion and exclusion criteria, then title and abstract screening were done and lastly full text screening was applied. A total on (n=6) articles were selected for inclusion. See Figure 3.

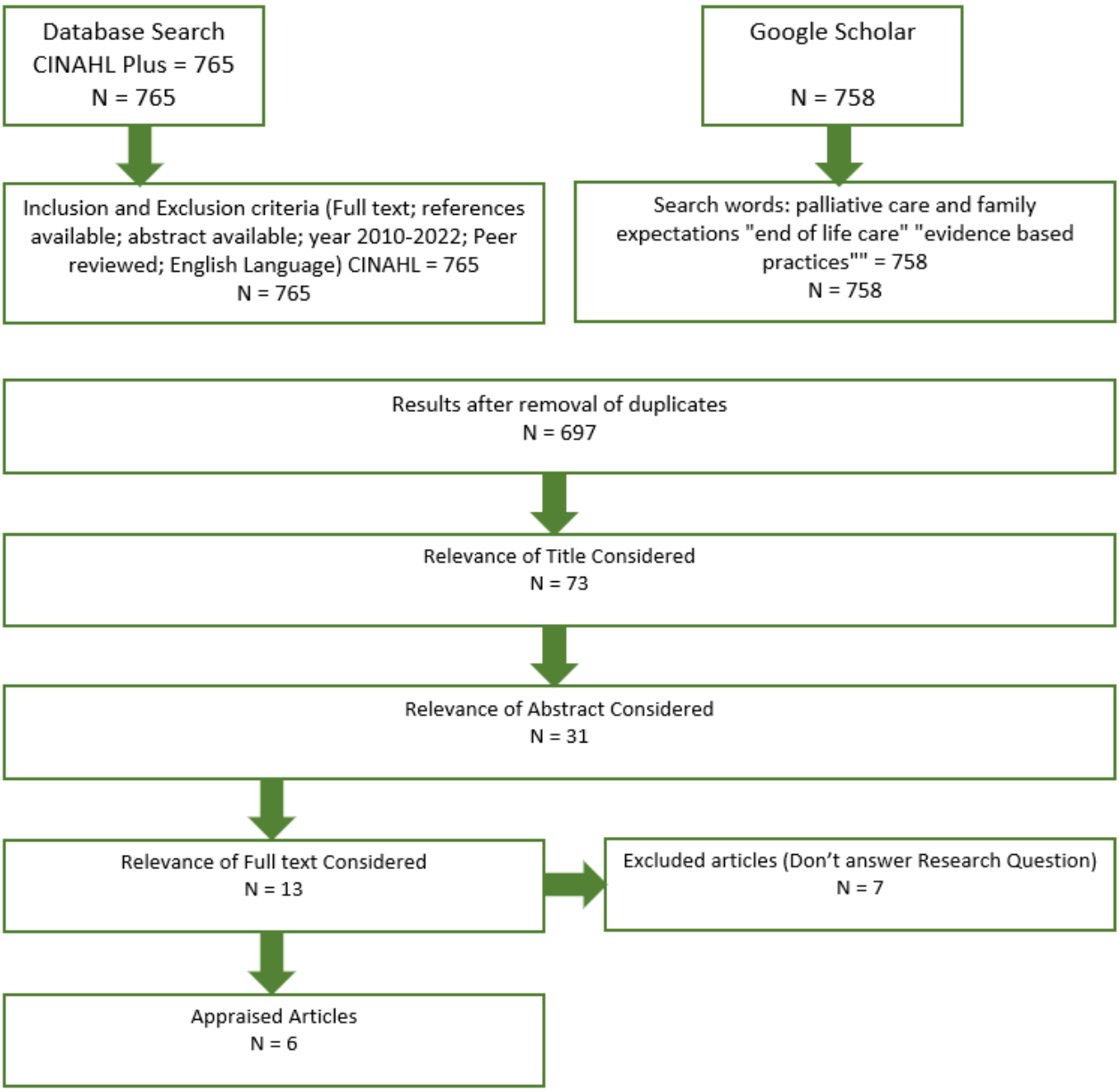

Figure 3. Prisma flow chart

4.3 Data analysis

The process of selecting articles is to show Figure 2 this was all done in tandem. Which authors had both been peer reviewed or had an abstract. The secondary process was finding articles that suited the research question which presented solutions today's problems using evidence-based researchers. The tertiary stage was reading in the depth the articles and making sense of six articles and how in each article the research question would be answered. "Data analysis is the process of systematically applying statistical and/or logical techniques to describe and illustrate, condense and recap, and evaluate data" (Robinson, 2004). According to Shamoo and Resnik (2003) "various analytic procedures provide a way of drawing inductive inferences from data and distinguishing the right articles

(the phenomenon of interest) from the nonevidence based articles (statistical fluctuations) present in the data. Various methods are used to analyse and present data depending on the type of study, research method and research approach. It can be statistical or non-statistical methods which can be thematic depending on whether one would have used qualitative, quantitative, or mixed research approach" (Shamoo & Resnik 2003). "The researcher may also opt for content or comparative analysis of the data. Analysis can also be deductive and or inductive basing on either one would have chosen research hypothesis or research questions". "A point to note is that data can be raw or secondary where raw data is obtained straight and direct from the subjects whereas secondary data is that which would have been collected before and stored in archives. The approach allows for an in-depth holistic understanding of the study while giving guidelines" (Elo & Kyngäs, 2008).

As per literature review study we gather data and further reduce it to make it more understandable to the lay man. Coding is introduced as method of simplifying, grouping subheadings and themes alike (Graneheim & Lundman, 2004).

Research Question	Themes	Subthemes
What are the expectations of family in elderly palliative care?	Racial differences	• Religion • Culture • Family dynamics
	Different set ups of palliative care	• Hospital • Home • Hospice
	Differences in time in palliative care	• Long term care • Mid term care • Short term care

Table 3. Outcome of content analysis

4.4 Critical appraisal

Quality os selected paper was evaluated using , Hawkers( ) checklist was introduced for a variety of tasks, method, data analysis, ethics, bias and transferability. The subsections are gauged between 1-4, and 4 being exceptional quality, 3 good, 2 OK and 1 poor. In the nine categories articles

were analyzed, evaluated and a score was given. Top points were pegged at thirty-six points and to qualify for the research an article had to achieve a minimum score of 18. The appraised articles that qualified are on a appendix page 39. The mean appraisal score 30.

5 Results

The six articles chosen gave a diverse range of answers to the research question. The six articles included in this study were published between 2014 – 2022 in China (1), USA (1), Brazil (1), UK (1), Canada (1) and Australia (1). The studies varied amongst the broad base of methods: Qualitative, secondary data analysis, narrative review, practice-based study and scoping review. The result of the analysis resulted in a variety of different sub concepts and gave a more in-depth perspective of nursing practices in both interventions and the ability to accommodate family expectations in different processes.

5.1 Racial differences

Race played a significant role in how well the palliative care was delivered and that a combination of socio-economic those that were satisfied or dissatisfied. Pain also differed in the two groups and the need for opioids and bowel movement was significant (Booker et al., 2020). Regardless of race, Palliative care is the absence of pain when the pain management is effectively planned. Nursing professionals must be fully trained to observe pain in different races, as in essence they are the ones that evaluate how patients are generally treated at the end of life (Espíndola et al., 2018).

Giving different experience and examples, and in mostly the African culture a decision for the care is carried out by the entire family, this in essence lessens the burden on the nurses, as it becomes a shared intervention with the backing of loved ones. (Booker et al., 2020) The Religion further gives assurance, comfort and gives that so needed safety needed. “All in all the meaning of life is sought at the end of one's life and it’s in knowing is that counselling, spirituality, religion or faith they feel committed and comfortable with” (Espíndola et al., 2018).

“Nursing professionals having a sensitivity on understanding that in some cultures family makes the decisions in end-of-life care. Children of the patient play a very pivotal role in assisting the health care professionals. Respecting all cultures and religions needs for further education as we assist the dying” (Williams et al., 2014).

With the influx of human diversity coming from within society and abroad, a reeducation of new ways and trends on how to address and express is needed. Acknowledgment of a variety of patients is essential for all health care professionals. The risk of undermining people's culture can happen without knowing, though these different experiences enrich the health care professionals understanding of patient needs, so listening to both the family members and patients is important and allowing them to be part of the process. "As the world turns to being one global village, we get to learn about different attitudes, wants and needs and put them together to make a suitable and appropriate care plan". (Lakasing et al., 2014).

We understand the many roles of a nursing teams is to advocate for people in need. The various processes involved do encourage patients to fight on to the very end. The task of a nurse in conveying vital information in a delicate manner, required empathy and constant team support to understand dying is a natural process of life and a full life should be admired. (Lakasing et al., 2014).)

During the duration of the palliative care, family members alter the course of their lives due to the illness, decision making on treatment, coordinating loved ones wanting to visit and trying give strength to other more vulnerable family members. The process can drag on for up to 12 months and it's the feeling and understanding of oneness that gives hope. Hope never disappoints. A hierarchy is created as decisions must be quickly made, this differs from country to country. At times the patient is deprived of the actual information of the progression of the disease in hopes to keep his spirits up (Bin Lai et al., 2018).

We also discovered that these are complex situations above board. New roles are established and family members work towards one goal of togetherness, honesty in interaction is key (Espíndola et al., 2018) . We realized changes over time, race, diagnosis, age social influence and wealth. A full life is said to be lived until 75, and understanding of what's about to occur was easier as they got older. "Finances and education played a role in getting the most effective palliative care and not forgetting interaction with family members" (Bin Lai et al., 2018). The inclusion of family members helps the patient to adjust and improves his mental wellbeing, family is everything. A full circle in life is death and that life must continue without you is hard to understand but its confirmed, when it continues and they acknowledge your time on earth (Espíndola et al., 2018).

5.2 Different set ups of palliative care

Different set ups of dementia palliative care included hospital, home and hospice. As is general knowledge palliative care comes in different forms and it's provides patients the willpower to decide in what location they choose to get this so crucial care. “As with any kind of palliative care the conversation are difficult and the communication should be good and clear in the benefit of the patient” (Espíndola et al., 2018).

As with any issue it's ideal to tackle it in the beginning stages. Relationships must built early on in the diagnosis stage that care plans that suit the individual are created in good time. With decision making on palliative care its ideal that they is a central person e.g. a wife, parent that knowledgeable that makes the tough calls in a short time frame, this leads to care improving and progress being made without any back and forth. Palliative care needs understanding, understanding the background of patient be it spiritual or cultural responsibility. E.g. Muslims men might find it uncomfortable being taken care of not facing Mecca, these are things that are very trivial to some but mean the world to others. “At times nurses might find it impossible to extend their views to family members but all this comes with experience” (Booker et al., 2020).

Hospital tends to be the short-term care provided as the care involved many disciplines in the health care team. Patient is usually transferred to a more suitable hospice. Dying in any hospital somehow feels impersonal and the general ambience of a hospital is unpleasant to many. Nurses tend to advice but never give direct orders to avoid future conflicts. The preference of palliative care is generally given by family members considering what can financial capabilities are available, that’s where being at the hospital would be an easier choice as nurses are in abundance. As health care workers, it’s important to give plain and simple factual advise, and leave the family and patient to conclude on what's ideal, it's always hard to deal with death and the truth can be sometimes unpleasant but that's the job. “Identifying the need for hospital palliative care proved to be difficult and the challenging aspect was that timing of when one should receive it showed a lot of work was needed in future” (Lakasing et al., 2014).

Patients living in care homes or own homes, had a better passage to end of life when they agreed to end their life there while accommodating friends and family in a home like environment. The presence of constant health care providers was essential. Dignity was more observed. A full life is a

life lived over 80. “The most challenging of palliative care is the length in how long a patient should get this care, some palliative could be active when we constantly monitor values and give medication this can draining to the family members as we now live in global village and people are busy with their lives” (Williams et al., 2014).

The presence of family helps in home care and to put depression away. The initial stages of home care can be so overwhelming and rewarding when you see loved ones. It's important that in the process communicating with the family is accurate so that they know what's being asked of them as misinformation can lead to a feeling of failure. Clients with no lethal diseases were slightly overrepresented and serious avoidance of discussing death in cancer patients (Lakasing et al.,2014).

This engaging can lead to advice and support for further training and raising the quality of care, family member might feel that they don't want to get their hands dirty and leave all the care to the nurses, which leads to care workers having to deal with emotional and physical aspect. Timing in care was essential but who in the process was to give that care and in which set up. Female spouse's bore the burden of taking care which had negative impact on the health of the female care giver. “Home care services were impersonal and limited to time and long-term care in the home or hospital give the impression of abandonment. An all-out family contribution was key” (Williams et al., 2014).

Hospice is a phenomenon that's yet to be fully used in the betterment of palliative care. It's a designed way of caring which knows no ages or racial groups. Hospice in essential is the stopping of wanting to cure the patient but instead giving extreme comfort and applying quality pain management. “The process of care has no location and can be administrated in hospital or in the comfort of your home. Medication that’s deemed helpful or prolonging life are continued” (Bin Lai et al., 2018). In general family members felt more part of the team when hospice was enforcement. New ways to further make care for them better. The use of pictures or signs to understand their very needs, use of bathroom, pain levels and freedom to roam around. Care can only improve with more staff and people will adapt new ways (Pu & Moyle, 2022).

5.3 Differences in time in palliative care

Palliative care nursing is challenging in many ways especially with the growing global village of nurses from different countries looking for greener pastures. Challenges come in different forms and shape, at times family not accepting the nurse on duty nor accepts that their loved one is dying. Many a times that medication is so aggressive that it leaves their loved one deformed or unfamiliar to them. “Length of care play also massive role, and family member might feel the nurse on duty yesterday didn't over sedate their loved one unlike the nurse on duty and that can cause uncomfortable confrontations because of differences in care by nurses” (Booker et al., 2020).

A feeling of failure sometimes occurs when nurses are swamped and overworked with work and have a feeling distress. This on many occasions can lead to nurses making mistakes and overlooking the obvious or giving adequate attention to all patients, other groups might feel they are being neglected and left to bear the burden of feeding and giving comfort to their loved ones. All this can have a horrific outcome if not dealt with in time, as emotions would be running high (Booker et al., 2020).

“Palliative care is outright tormenting to new nurses, steady hands and relying on evidence-based care is essential. Dealing with death or dying people needs one to understand that it's a process and if the pain is managed, half the job is done” (Booker et al., 2020).

In the research, it was evident that not all health care professionals had been guided or given further education by their supervisors or organizations. Others had very little training in health care but did what they could considering the situation. “Dealing with different families, religious people and races needed adequate training so as not to offend patients and family members” (Pu & Moyle, 2022).

The question of the study was answered using the data, palliative care is not a death sentence but a slowed down effective way of giving health care to a patient whose terminally ill. “Giving adequate information of the illness, timely medication, pain management and forth right communication that accommodates the patient and family at the end of their life” (Booker et al., 2020).
The duration of the palliative care varied according to age, financial ability, aggressiveness of the diseases and quality of care given by specialists and family members. Hospitals in general did not

give the required feel good factor for the dying patients and was perceived to be a short term stay under 14 days. Midterm palliative care ranged from 14 days to 90 days. Whereas long-term ranged between 6 and 12 months. Understanding the need and availability of care is yet to be fully understood and its pros and cons. Limitations on the actual stay in palliative care units and affordability where vastly unanswered and at times took for granted the health care provided in the Nordics as the norm for all countries (Booker et al., 2020).

“Women usually bore the burden of caring for husbands or children, the effects of this were detrimental to one's health” (Williams et al., 2013). Further research and understanding palliative care are needed while encouraging people to integrate in earlier stages.

The shortcomings faced by nurses varied on a daily basis. The issues ranged from miscommunication, race , family members feeling uncomfortable with the process and diagnosis. Advise from family members was welcome but couldn't override doctors order's regardless of their feelings and thoughts of not being enough (Booker et al., 2020). “Health professionals felt overwhelmed and unworthy. The fact of being in a palliative care unit was strenuous enough let alone the fact also helping the family to come to grips with losing a loved one to a terminal illness” (Lakasing et al.,2014).
Giving care to palliative care patients is a very tasking job as it’s a combination of skill , empathy and learning new skills/cultures on the spot. Those that were positive lived longer, learnt new things along the way and were able to have a respectful end thus finding end of life as a natural process of life (Williams et al., 2013).

Most communication is nonverbal, discussions had with the patients privacy policy and what were the patients views on it. Would all information be open to all or just the next of kin, to then give appropriate information to the rest of the family. Death for many is a scary concept, some leave it to late and can't manage discharging their wishes. Communicating truth without removing hope and addressing the illness and other unknowns (Pu & Moyle, 2022).

The sooner palliative care is started the better and a good solid pain management plan is made. Respectful conversation on an holistic approach in context with evidence based fundamentals so as to give adequate quality care in a individual by individual basis (Bin Lai et al., 2018). The health

care professionals should constantly be trained on diversity and new methods of care as palliative care was still in the doldrums of giving multidisciplinary care (Bin Lai et al., 2018)

6 Discussion

The aim of the study was to investigate on the expectations of the family on palliative care. The research findings show that families had varied expectations. The research was a literature review. In addition, WHO, (2017) note that "palliative care in home settings improves quality of life and reduces cost". Past studies have revealed that home setting may result in the patient having less anxiety, aggression and some cases agitation (Zeisel, 2013). In concurrence Fleming et al., (2015) asserts that "a home environment result in the patient the patient being calm and in complete harmony with his or immediate environment". Zeisel (2013) observed that "a home environment cement relationship between the patient, the nurse or social worker and the family". Counseling is important in relieving stress on both the patient and the family and prepares the family for mourning their loved one if he or she dies (WHO, 2017).

The research findings show that the families understood counseling and its significance during the end of life of the patient. The families underscored the importance of counseling to the family, relatives, and the patient. Counseling assist in reducing sickness, takes of pressure from individuals and build trust between the patient, the nurse, and the family. Kamal et al., (2013) further note "effective counseling offers opportunity to both the family and the patient to open up. This has a great effect on the treatment of the patient and may assist in healing and improving quality of life".

Further analysis of the results showed that palliative care is regarded as a way of ensuring that the patient receives the best care possible during their last days. According to the WHO, (2017) "palliative care is more than relieving pain of the patient but encompasses the family". The organization noted that family and friends require counselling and need to prepare, adjust and adapt to the sickness of their loved ones and also prepare for the death of their relative. Palliative care also assist the family long after the patient has died by enabling families to cope during the mourning period (Global Atlas, 2014). The research finding are in tandem with WHO, (2017) who asserts that "palliative care should include the patient, family and relatives and help all cope with the sickness and make necessary adjustments and adapt during the critical period of the patient's illness". The inclusion of the family also prepares them to mourn the death of their loved ones. In accordance with the WHO, (2018) "patients and families are affected by challenges associated with life threatening

illness and they need palliative care to cope and take care of their sick patient with the aim of improving quality of life". In concurrence Espindola et al., (2018) notes that "palliative care involves the inclusion of families and friends as a way of assisting them to cope and adapt to situations associated with acute illness and death of their loved ones".

These findings show that the majority of the families are opposed to informing the patient about his or her death. The families opposed to informing patients argued that informing the patient had negative effects and facilitates dying of the patient. In addition they reasoned that any form of negativity during this life critical period of the patient delay healing of the patient or lowers chances of prolonging life. The effect rather accelerates dying as the patient may lose any hope of surviving the illness.

From a paper by Pu (2022) the scoping review provides an overview of the available evidence of restraint use in residents with dementia living in RACFs. "The residents living in dementia special care units with specialized practice nurses may experience less restraint" (Bolt et al., 2014). Frequently, if staff used a person-centred approach where they learnt the resident's needs and responded to those needs, it is likely that there would also be less use of restraint. Therefore, an adequate staff ratio and sound knowledge and respectable attitudes towards restraint use are essential to improve the practice of restraint use in people with dementia living in RACFs. "Care staff often found it difficult to decide whether it is ethical and appropriate to restrain residents with challenging behaviours" (Ho et al., 2022). Decision-making is a complex trajectory which depends on resident characteristics, staff-related factors and contextual factors.

Therefore, "facilities should build guidelines for restraint use to promote alternative approaches to manage challenging behaviours of dementia. The use of restraint should only occur in extremely limited circumstances, and the reasons for restraint use should be clearly documented, including duration of use, regular monitoring of the outcome of restraint use and any adverse events" (Bellenger et al. 2019). "A guideline-based multicomponent intervention was reported to significantly reduce physical restraint use in nursing homes" (Köpke et al., 2012), but its effect on residents with dementia was unclear. Additionally, "the implementation of risk management practices, a formal method of balancing the probable consequences of decisions, and validating clinical decision-making processes" (Clarke & Mantle, 2016), is also essential to promote person-cantered dementia care.

Furthermore, care staff was encouraged to be trained and instructed in this process to balance ethical and safety values. The issue of restraint has been attended to in many countries by introducing regulatory approaches to the use of restraints, especially where a person lacks the capacity to give informed consent. For example, in Australia the Quality of Care Principles (Australia Government, 2019) require care providers to ensure assessment is carried out by approved persons and alternative approaches are tried and documented before physical or chemical restraint is used. In Norway, the use of restraint can only be used as a last resort. However, "despite such regulations, restraint continues to be used often because staff are not aware of alternatives" (Pu & Moyle, 2022).

Most of the interventions to reduce restraint have focused on staff education. However, "it is argued that many of these education interventions do not work as they are not person-centred, and do not build confidence in alternatives to restraint" (Pu & Moyle, 2022), and "the importance of the facilitator's role has not been understood and integrated into the education intervention" (Pu & Moyle, 2022).

6.1 Research ethics, validity, reliability and generalizability

The process of evaluating and interpreting evidence by systematically considering its validity, results and relevance. According to Haddad & Geiger (2022), "validity refers to a circumstance in which the outcomes are really about what they appear to be. Reliability defines the degree to which information evaluation strategies can produce regular findings. Reliability and integrity can be maintained through lowering the chances of error and bias". To decrease bias, respondents were asked to provide data anonymously to make certain confidentiality, and no names of individuals have been blanketed in the questionnaire as well as in interviews conducted.
In order to make sure the accuracy of the statistics received, all respondents had been contacted by way chosen to request their willingness to participate in the study. This also helps the researcher to introduce and familiarize the interviewees and respondents related to the surveys and to permit sufficient time for them. In order to make sure accuracy, the researcher contacted a few respondents after the interviews and asked whether the conclusions made had been in line with the statistics provided. The research additionally used to be protected through conducting a pre-test whereby the researcher used to be in a position to verify that the statements had been main each surveys` respondents into answering the statements honestly and reflect their own opinion on every proposition.

In addition, to make sure integrity and reliability, records were accumulated at the same time duration in order to prevent instances of members duplicating responses from fellow participants who could have been reached first. In addition, the triangulation of qualitative and quantitative methods used to be co-opted in the research to make sure validity and reliability. The researcher self-governing questionnaires that furnished clear and distinct guidelines for completion of the questionnaires. The due date for the completion of the questionnaires was given and this facilitated the return of the data. The research was once carried out bodily by using the researcher before questionnaires or interview classes were started. The researcher also ensured that confidential statistics are included by no longer revealing any confidential factors of records collection activities to unauthorized persons. Respondents were additionally informed that they were free to refuse or discontinue their participation at any time.

The researcher additionally used more than one sources of evidence. Erlingsson and Brysiewicz (2017) “define triangulation as cross-comparison between data sources, statistics collection methods, time periods, and theoretical schemes”. This was once executed via the administration of questionnaires accompanied through interviews with questions aimed at cross-checking the validity of the replies to the questionnaire. The contributors ' responses to questionnaires were additionally validated by means of evaluating them with interview responses. As a result, “triangulation facilitated an evaluation of exclusive sources and methods to decide whether or not some patterns proceed to recur” (Guo et al., 2019).

Both quantitative and qualitative methods can be regarded inadequate by themselves to seize the developments and important points of the state of affairs. By the use of both qualitative and quantitative research, the reliability and interior validity of the records have been extended and any plausible weaknesses in the statistics gathering strategies have been reduced. With the aggregate of distinctive methods, extra statistics and data have been generated from one of a kind perspectives and unique angles in order to amplify the accuracy and validity of the findings of the study. Besides, the survey did now not encompass ‘no opinion’ or ‘do now not understand’ chances have been deliberately left out in order to barely pressure an opinion from all respondents and stimulate them to answer all statements. The inclusion of the ‘no opinion’ or ‘do no longer understand’ may want to have additionally given respondents the chance to select the convenient way out in answering the statements if they had problems with appreciation it. In the cowl letter, respondents were urged to ask for clarification if a declaration was doubtful to them.

6.2 Ethical consideration and limitations

"The study ethics were observed during the research and understood the need to be guided by principles and honest procedures" (Gray 2020). In a Global village that we all reside, giving an in-depth account of current matters so as to expand and increase studies on further palliative care research is imperative, we stand to give credit, and adherence to the authors who were used as references. All the articles used were peer reviewed were taken from the JAMK university database and Google scholar. The JAMK university guidelines were there to literally guide this body of work which avoided any piracy (Gray, 2020). The research findings were palliative care with family expectations. Research was done on Google scholar and the schools database which was limited and focused only on English articles. As more and more nurses, with different backgrounds interact these studies forge harmony and an understanding. Further reading of articles will give an in-depth understanding to different scenarios that nurses and patients face in the future.

7 Conclusion

This study came to the conclusion that palliative care and hospice is two very things. Palliative care means unburdened and allows a team of specialists and gives the opportunity for a prolonged life, the care is good and is slowed down unlike hospice care that has a time limit of on average 6months. This study also found the emphasis on the importance of pain relief, diversity in the team and most importantly to be understood in your time of need. Compassion from the nursing team and family members gave an instant boost. Personal goals are observed which accommodate family and friends, in essential this is what palliative care is.

An end-of-life service network that could benefit patients with life-threatening diseases, and that could be set up in institutions at all three levels, should be developed. The obstacles impeding the development of end-of-life care should be resolved before a comprehensive end-of-life care system is established. Based on the research findings, it was observed that some families lack adequate knowledge on palliative care. It is therefore recommended that, the primary ministries responsible for health and social welfare develop a communication mechanism to educate citizens on the importance of palliative care of the elderly. Both public and private hospital should have affordable palliative care units to increase access and ensure that the patient and the family experience less negative effects of life threatening illness being experienced by their patient. The government

should train more care nursing assistants to allow palliative care to be done in home settings thereby lowering costs on admission and congestion of hospitals and other care centers. This also enables families and the patient to have access specialized and tailor made palliative care as the nurse will be mainly focusing his or her attention on a single person.

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APPENDICES

Appendix 1. Summary of reviewed articles.

	Authors, Year, Country, Title	**Purpose / Aim**	**Research Methods or Instrument**	**Main results**	**Critical appraisal (Hawker et. al 2002)**
1	Bin Lai, Xiao; Wong, Frances; Kam Yuet, Ching; Shirley Siu Yin. 2018. China. The experience of caring for patients at the end-of-life stage in non-palliative care settings.	Understanding of different cultures, races and the inclusion of religion in a non-palliative care set-up.	Qualitative study	Family dominated decision making and what the future holds in non-palliative care. The majority of patients were in secondary or tertiary care. Health care workers provide additional care both in giving information and nursing procedures. Further education to be rallied to the public to ensure the quality of care is improved.	32
2	Booker, Staja Q; Herr, Keela A; Garvan, Cynthia Wilson. 2020. USA. Racial Differences in Pain Management for Patients Receiving Hospice Care.	Understanding race, diversity and expectations of family members.	Secondary data analysis	The need for individual pain management differed amongst races. Disparities in socioeconomic factors differed. Their spiritual connection determined tolerance levels. Education on patient rights.	28
3	Espíndola, Amanda Valério; Quintana, Alberto Manuel; Farias, Camila Peixoto; Bade München, Mikaela Aline. 2018. Brazil. Family relationships in the context of palliative care.	To explore the family dynamics in palliative care.	Narrative review of literature	Family bonds grew stronger and people took up roles to support their loved ones. Dignity preserved and the need for firmer spiritual life reaffirmed. An interference at times with health care workers and boundaries at times broken unintentionally by family members. Clearer rules and further education crucial.	28

4	Lakasing, Edin; Kulkarni, Sadhana; Sparkes, Carly; Ravichander, Radhika. 2014. UK. A practice-based survey of patients dying in hospital: can we do more to support end-of-life care at home?	Differences in set-up of palliative care.	Practice based study	Home base nursing and hospital base nursing was equally as good. The fear of family members resulted in less of end of life care at home. Developing newer and more care appropriate in home setups. Easy to use gadgets. The different types of insurance provided and which other experts can be included in case of emergency.	30
5	Williams, Allison; Wang, Li; Kitchen, Peter. 2013. Canada. Differential impacts of care-giving across three caregiver groups in Canada: end-of-life care, long-term care and short-term care.	Getting a broader view of the different nursing teams with the expectations of the family members.	Literature review	The diversity of nurses was crucial and that family members were a part of the care plan as relationships built in a vulnerable set-up are long-lasting. Main components in delivering care and the hierarchy of it. The involvement of family and nursing team and their limitations while giving care. Goals drawn up and achieved. Checking of emotional, pain levels and spiritual connection and needs of the family.	32
6	Pu, Lihui; Moyle, Wendy. 2022. Australia. Restraint use in residents with dementia living in residential aged care facilities.	To understand palliative care even in people with dementia.	A scoping review	The inability to express themselves led to sometimes over restrain and further education was needed for staff to cope with an ever-growing elderly population. Assurance of safety in the home and in society. Needs, expectations and fears addressed. Pain and stress to be addressed to make living more comfortable.	28