REVIEWS

Exploring various models of hospice care worldwide that can be used and adapted to the context of Qatar: A review of the literature

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ABSTRACT

Background: Hospice care is an alternative for those patients who wish to die at home. Most clients who have a terminal illness would rather choose the services provided by healthcare workers who deliver hospice care in the client's home. For some, it is important to have the ability to spend time with friends, family and to die with dignity and respect at their preferable place of death. Qatar has established end of life care services for patients with advanced stages of cancer, however these services are delivered on palliative care units housed within the National Center for Cancer Care and Research (NCCCR). Having the ability to provide at home hospice care is a necessity in order to carry out the wish of clients who wish to die at home, fulfil the gap in these facilities, and achieve the goal of Qatar's national health strategy, which is to improve cancer services.
Aim: To explore the literature for different models of at-home hospice care worldwide then find a model that can be adapted to the context of Qatar.
Methods: A literature review approach was used. Nine scholarly articles were found that focused on and evaluated different at-home hospice models of care worldwide published between 2007 and 2018. Articles were critically appraised using the Mixed Method Appraisal Tool. The data were analysed by categorizing the included articles in a spreadsheet based on study design.
Results: The most significant components of at-home models of hospice care were multidimensional care, staff competent in delivering end of life care services, and the ability to provide twenty-four-hour care in the home. These components had a positive impact on providing safe effective end of life care services at home.
Conclusions: Taken together, all the necessary components identified in this literature review will go a long way in the successful development of hospice care in Qatar.

Key Words: Hospice care, Home health care, Cancer, Community care

1. INTRODUCTION

The incidence of life-threatening illness such as cancer is increasing worldwide. The World Health Organization (WHO) statistically assessed that cancer related deaths will increase globally and will approach up to 13 million by 2030.[1] Brown et al.[2] estimate that by the year 2030, developing countries will face 70% load of global cancer. The developing countries in the Middle East will have the majority of newly acquired cancer cases by 2020. Global healthcare systems require health care strategies that prevent, mitigate,

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and detect early cancer, while improving the quality of patient and family life of those suffering from cancer. The Qatar National Vision (QNV) 2030 is one such strategy. It is based on four pillars; the most significant one is human development. People are the most valuable asset that contributes to the country's development.[1] Because they are a valuable asset to the country, the government has a responsibility to take care of people's health. The Qatar National Health strategy recommends expansion and advancement in health care systems and education which will help in human development.[3] Several new health care facilities have been developed in Qatar to target different patients. The purposes of these facilities are to provide safe, holistic, and accessible health care services to all people in the community. The National Center for Cancer Care and Research (NCCCR) is one example of these several new services that target the population of people that have a diagnosis of cancer.

The NCCCR was created for excellence in cancer care and research as one of the goals of the QNV. In 2008, a palliative care unit was established at this ten-bed centre.[4] Palliative care seeks to improve the quality of life of patients and families suffering from terminal illnesses such as cancer.[5] Palliative care units aim to provide end of life care and symptom management for patients who are terminally ill.[1] With the increased incidence of patients with cancer and the limited number of beds, a plan is necessitated to meet the demands for an increase in palliative care services.

Currently, there are no provisions in Qatar for people who wish to die at home let alone the qualified and skilled staff to support this. Thus, the purpose of this literature review was to explore the literature in various countries to see if a model of hospice care is available that can be adapted to the context of Qatar.

2. METHODS

2.1 Literature search

The following search terms were identified and used to search for literature: *Hospice care, Hospice, Hospice at Home, Home health care, Home care, Community care, Community health care, Home environment, Health care delivery*, and *Cancer*. These search terms were used in the following search databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, and Academic Search. The search result was narrowed by using search limiters. These limiters were English language, peer -reviewed, and publication date from 2007 to 2018. The search resulted in 44 articles from CINAHL, 36 articles from MEDLINE, and 33 articles from Academic search.

2.2 Data evaluation

After applying exclusion and inclusion criteria and further review a total of nine articles remained. The exclusion criteria were articles that discuss hospital- based hospice care models, articles that include paediatric hospice care, and articles that did not include patients with terminal illness. Forty-three articles were excluded after reviewing the titles and abstracts. The full text was reviewed of the remaining 19 articles to identify articles that describe and examine the different models of hospice palliative care at the community level through experiences and perceptions of stakeholders. After final review, nine articles were found to be acceptable for inclusion in this project.

2.3 Data appraisal

All nine articles were critically appraised using the Mixed Methods Appraisal Tool (MMAT) version 2018.[6] This tool was developed in 2006, reviewed in 2011, and last updated in 2018. This tool is comprised of two stages: the first stage has two screening questions for all types of studies and the second stage has five questions to evaluate the specific types of study. These five questions are used to critique the literature and required a response of either yes, no, or can't tell. This tool measures the methodological quality of studies, validity of studies, and relevance to the study question. Four of the studies were qualitative in their design and met all five of the required criteria, such as research question, data collection, finding, and interpretation of results. Only one qualitative study, that was a case study, did not meet all five criteria due to an unclear method by which data were collected and analysed. Two of the studies were mixed method in their design and were assessed for effectiveness of both the research question and integration of the method used to assess, interpret, and report it. Two of the studies were quantitative non-randomized in their design and met all five of the required criteria, such as representativeness of population, completeness of outcome data, and accounting for confounders in design and analysis. These nine articles met the MMAT criteria. Therefore, the literature results included in this project are reliable and valid.

2.4 Data extraction

Data were organized and summarized in an Appendix. The nine articles were presented in chronological order according to the method used and year of publication. The Appendix includes the authors' names, year of publication, country, study purpose, method, design, sample size, type of models, results, and limitations. This Appendix helped in presenting the data, finding similarities and differences, comparing and highlighting results, and synthesizing the relevant information in order to recognize the common themes among these articles. Three common themes that emerged from these articles are: to provide multidimensional care, to provide staff competent in end of life care, and to provide twenty-four-hour services seven days a week. The main focus of all these articles was to evaluate a model of hospice care at the community level to see if these models could be adapted to fit the context of Qatar (see Figure 1).

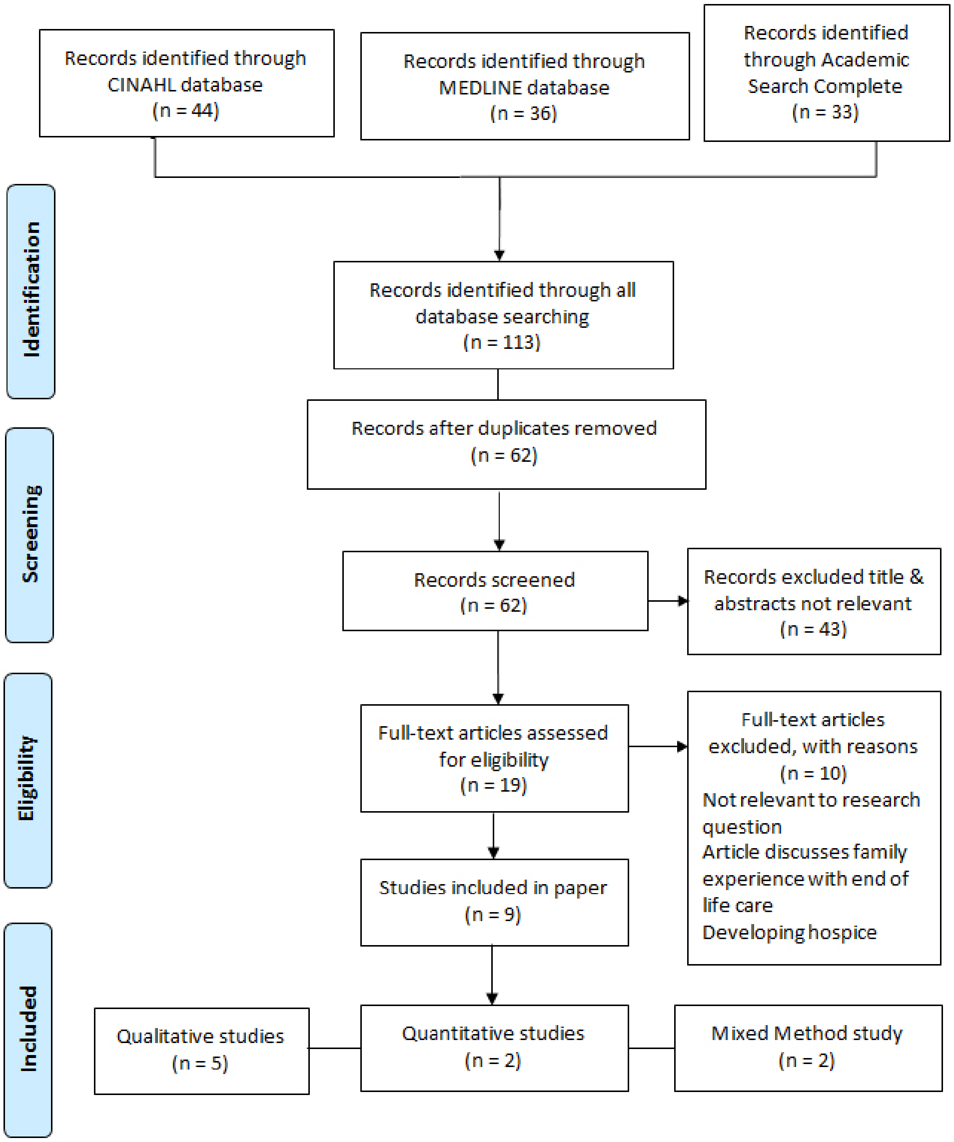

Figure 1. Flow chart of search results of studies from searching and screening

3. RESULTS

Although there are numerous models of hospice palliative care worldwide, this literature review focused on only those articles that evaluate models of hospice care which were either home or community based models. The nine articles were published between 2007 and 2018. These were primary study resources including three approaches: qualitative, quantitative, and mixed method research studies. These studies were conducted in different countries and regions: Australia (n = 1), Canada (n = 2), China (n = 1), Netherlands (n = 1), Singapore (n = 1), sub-Saharan Africa (n = 1), and United Kingdom (n = 2). These studies used different types of designs. The five qualitative studies used phenomenology, qualitative description, and case study. The phenomenology study by Aoun et al.[7] evaluated the model of care that included the use of personal alarms and the home care aid model at home and the experience of terminally ill patients who utilize this model. In a qualitative descriptive study, Marshall et al.[8] evaluated the ability of a family physician to provide quality palliative home care by utilizing shared care model. In a case study, Jack et al.[9] explored hospice at home model of care through patients' and family caregivers' perception and experience. While in another case study, Sussman et al.[10] examined palliative care programs for cancer patients in four regions in Canada that delivered end of life care at home. Yin et al.[11] described three hospice palliative care programs in China that were similar in their design. Two quantitative non experimental studies using a retrospective cross -sectional design evaluated hospice palliative care programmes at home or at a community level in both Netherlands and Singapore.[12, 13] The final two studies were mixed methods. One of which Downing et al.[14] evaluated three hospice palliative care models in Kenya and Malawi while Jack et al.[15] study examined hospice at home services model based on the experience of health care professional in their delivery of services. Based on the above articles, the three themes that have emerged as the most important aspects of at home hospice palliative care models were: to provide multidimensional care, staff who are competent in delivering end of life care, and to provide twenty-four-hour services seven days a week.

3.1 Multidimensional care

To relieve and prevent multidimensional suffering of terminal illness in patients and families, multidimensional care in the models of hospice palliative care in the home had a significant role in optimizing their quality of life.[8–10] Nine of the reviewed articles showed that models of hospice at home care utilizes a holistic approach to providing end of life care for patients with terminal illness and their significant others.[7–15] These articles also revealed that healthcare providers provide multidimensional care, such as physical, psychological, social, and bereavement support for patients and families in order to decrease suffering. They also went on to say that the models of hospice at home care provided physical support through managing disease symptoms such as pain. Healthcare workers provided holistic care and both understood and assessed an individual's needs within the preference of the patient. According to Anoun et al.[7] physical support can influence psychological well-being in a positive way as one participant elaborated:

> (Care aide) is marvellous. I would say sixty percent, she's helped. I asked if she could help chop up the vegetables, and she said: "Sit down and make a cup of tea for yourself. She made me a big pot of soup and put it in five different containers and put them in the freezer."

This combination of physical and psychological support while preparing the meal and having company at mealtime psychologically improved the patients' appetite and encouraged her to eat more. In their study, Yin et al.[11] explored patients and families experience of psychosocial support as one dimension of at home hospice care. These patients and families perceived that these models socially support low-income patients by providing free treatment, spiritual care, and bereavement support for their families during and after the disease trajectory. Jack et al.[15] explored the experience of palliative clinical nurses specialist in hospice at home models of care. These participants stated that family members felt reassured and valued the effort made by the CNS and healthcare providers while transferring patients' home to fulfil their wish of an at home death. Tan et al.[13] stated that the utilization of a comprehensive approach to at home hospice models of care, significantly resulted in the reduction of emergency room visits and hospital deaths. In their study, Sussman et al.[10] reported a greater probability of home death with appropriate utilization of multidimensional care. Multidimensional care should be a part of at home hospice models of care because most terminally ill patients preferred to die at home. These dimensions in care will provide an important opportunity for meeting patients' and families' expectations and achieving the goals of care for those who wish to de at home. Providing effective multidimensional care requires competent staff to provide end of life care.

3.2 Staff that are competent in delivering end of life care

All studies highlighted the crucial role of healthcare providers knowledge and skill in providing end of life care at home.[7–15] These studies showed that specialized medical knowledge, skills, and knowing what to expect when it comes to terminal illness enabled healthcare providers to provide end of life care. The authors of these studies found the competence level, training, and expertise of healthcare providers and noted it to have an make a difference in the quality of care provided to patients and families which ultimately influence their quality of life. For example, Jack et al.[9] stated that the nurse was able to manage a patient's mouth dryness at night time by instructing him to use artificial saliva at bedtime. The ability of this healthcare provider to recognize signs of deterioration facilitated symptom management of the patient. Besides the cognitive ability to understand the trajectory of the disease to manage the patient's condition, healthcare providers should also be aware of culture, values, and beliefs of patients and families in order to provide culturally appropriate end of life care.[11] Cultural competencies help to establish trust and therapeutic relationship between patients and healthcare providers which in turn helps to facilitate provision of end of life care. Aoun et al.[7] stated that cultural competencies preserved a sense of dignity. One participant in this study felt that her privacy was maintained and her beliefs were respected while receiving a bath. This made her feel more valued, which enhanced her quality of life. To ameliorate care provided to patients and families, healthcare providers require continued education, training, and updating knowledge about the end of life care.[2,8,9,12,14,17,24,25,27] Providing a special educational session about end of life care to community nurses, primary healthcare providers, and general physicians enables healthcare providers to provide safe effective end of life care at home in the community.[8,14] Patients and families also benefit from competencies, knowledge, and skills of healthcare professionals when the services are available twenty-four-hour seven days a week at home.

3.3 Twenty-four-hour care

All studies showed that twenty-four-hour care is an important component for at home hospice models of care to improve the quality of end of life care provided to terminally ill patients and their families.[7–15] De Graaf et al.[12] stated that in the Netherlands, healthcare providers integrated hospice care in the primary health care system to fulfil patients' wishes and reduce their suffering by providing twenty-four-hour end of life services at home. Jack et al.[15] reported that collaboration between healthcare providers facilitated providing twenty-four-hour end of life care at home especially if patients are in a crisis situation. One palliative care nurse specialist in this study advocated for the patient by consulting with a general physician by phone to make a decision about keeping an acutely unwell patient with a brain tumour at home because it was not safe to move him and the family preferred to keep him home. Aoun et al.[7] found that twenty-four-hour telephone services in home hospice models of care increased the feeling of physical security and improved the experience of end of life care of patients living alone at home with terminal illness. A rapid response team and night services in home hospice models of care help to improve the trepidation some patients and families may feel whilst dying at home. The caregivers in these models watch for the signs of deterioration to reassure the patients and reduce and the burden from family members.[8–11,14,15]

4. DISCUSSION

The purpose of this review was to find a model of at-home hospice palliative care that can be adapted in Qatar. There are several components of at-home hospice palliative care models that can fulfil the current gap at end of life care services and accomplish wishes of terminally ill patients and their families. In the literature review, there were three important elements that must be included in at-home hospice model of care in Qatar: multidimensional care, staff that are competent in delivering end of life care, and twenty-four-hour care.

Multidimensional care was the most critical and common element in at-home hospice palliative care models in the literature included in this review. Utilization of the holistic approach by health care providers in assessing and providing end of life care services had a positive impact on the quality of life of terminally ill patients.[7] A comprehensive approach helped those home health workers to provide care to fulfil the physical, psychological, social, and spiritual needs of patients and families in order that they may die with dignity and respect at the preferred place of death. Khumalo and Massdrop[16] agreed that a comprehensive care element is critical in the model of at-home hospice palliative care. They state that health care professionals in the Island hospice model of care deliver care and treat individuals in a manner that seeks to enhance their quality of end of life care. Some of the features of this model include home visits, roadside clinics, and walk-in clinic services. The Island hospice model services also continue after death by providing comprehensive bereavement care for families and relatives. Spencer[17] reported that the integrated model of community specialist palliative care delivered holistic end of life care services by enhancing the collaborative work of multidisciplinary teams to facilitate complex end of life care services at home. Furthermore, Tan et al.'s[13] study showed that utilization of a comprehensive approach to at home hospice model of care is beneficial for systems and organizations by reduction of emergency room visits and hospital deaths. Likewise, Brumley et al.[18] found that at home palliative program was cost-effective by cutting hospital expenditure from $212.80 up to $95.3 per day. Providing comprehensive care improves the quality of care provided for patients, families, and systems is achieved through having staff that are competent in delivering end of life care.

Healthcare providers' knowledge and skills have proven to be an important part of at-home hospice palliative care models. All of which must be considered in order to deliver a compassionate, holistic, and safe effective end of life care services at home. Understanding the trajectory of a terminal illness and recognizing signs of deterioration facilitate the work of nurses to effectively manage the symptoms of patients at home.[9] Choi et al.[19] supported this view. Their study showed that "nurses who worked on cancer units and who had previous end-of-life care education had higher scores on knowledge of end-of-life care." Therefore, quality of end of life care improved significantly. Spencer[17] reported that advanced practice knowledge and skills of clinical nurse specialists helped in reducing patients and families suffering from symptoms of the terminal illness and improved their quality of life. Continuing education was found to be the most effective means of increasing knowledge and skills of healthcare providers who work to provide good quality of end of life care.[8, 11] Yin et al.[11] reported that culturally appropriate end of life care can be provided through staff awareness about the culture, values, and beliefs of patients and families. The American Nurses Association (ANA) stated that "knowledge of cultural diversity is vital at all levels of nursing practice."[20] They reported that in Muslim culture the practitioner awareness of religious preferences is required to provide culturally competent end of life care. This helps the practitioner to deliver spiritual support and care according to Muslim spiritual-religious beliefs and needs at the end of life. Choi et al.[19] suggested that to provide comprehensive end of life care and to improve the quality of care, continuing education programs should be provided for healthcare providers to achieve the optimum end of life care. Johnston et al.[21] found that joint training and collaborative work between general physicians, district nurses, and specialist palliative care teams increased the knowledge amongst non-specialist services. Allo et al.[22] had a similar result. The majority of participants in this study valued the patient home visit educational program that was very effective in upgrading knowledge and skills of community staff. This valuable knowledge and these skills of healthcare providers can benefit a community by providing twenty-four-hour end of life care services at home.

Twenty-four-hour care has been shown to be pivotal in enhancing the quality of life of patients with terminal illness including that of significant others in at-home palliative care models. The sense of physical security was increased for patients living alone at home with the terminal illness by providing twenty-four-hour call services in end of life care.[7] Yeager et al.[23] had similar findings. The emergency phone line services in their study improved management of disease symptoms such as managing worsening pain and intractable vomiting by giving additional doses of medication. Sarmento et al.[24] also agreed that the availability of twenty-four-hour end of life care services such as home visit results in relieving disease burden from the patient and family through sharing responsibilities. Jack et al.[15] reported that the teamwork among the healthcare providers facilitates the delivery of twenty-four-hour end of life care services at home. Grant and Scott[25] also found the collaborative effort between healthcare providers and caregivers helped in fulfilling the wishes of patients to die at their preferable place of death with dignity and respect. It is hoped, these collaborative efforts will lead to an increased sense of security and less uncertainty. Robinson et al.[26] reported that around the clock service at home was recognized to be one of the enabling factors that facilitate caring at home until death. This service could be delivered in the form of the rapid response team and night nursing services which helps to achieve the desires of patients nearing the end of life.[27]

5. CONCLUSION

An overview of the literature explored the most significant and common components of at-home hospice model of care that have positive impacts on quality of end life care for terminal illness. The significant and common components among reviewed models were multidimensional care, competent staff at end of life care, and twenty-four-hour care. Studies demonstrated that use of these components had positive outcomes such as reducing the patient suffering through managing disease symptoms, providing psychological and emotional support, and providing social support to reduce the burden of disease from the family. These components also increased the sense of physical security through having qualified culturally competent staff at end of life care who provide continuous different services at the community level. These staff enhance patients feeling of dignity and respect by fulfilling the wishes of the patients to practice their cultural and religious ritual and to spend their last days of life at their preferable place of death. The reviewed models provide an opportunity to save cost through reducing time spent in hospitals, decreasing the number of emergency visits and admission to hospital, and improving the quality of care by increasing the capacity and staff retention. In Qatar, stakeholders need to consider these significant components to initiate at-home hospice model of care to enhance end of life care as per patient's wishes and satisfaction.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare no conflicts of interest.

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