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# Caring for the dying patient and his family at home : a literature review



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**Support given by nurses to the dying patient and his family  
at home: A literature review**

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## Support given by nurses to the dying patient and his family at home

### A literature review

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The purpose of this review was to illustrate how current literature has described the support that nurses provide to the dying patient at home as well as his family. The research question in this study was: how do the nurses provide support to the dying patient and his family at home. The thesis was carried out under the safe home project of the Laurea HANKE forum.

The review specifically describes nursing support to the dying patient and his family. The method applied in the study was systematic literature review. The literature search was based on previously published studies, which included; current articles, journals and web articles. The data was selected from literature search by their relevance to the research task, and analyzed through inductive qualitative content analysis.

The findings showed the different ways the nurses with the help of other professionals support the dying patient at home. The findings revealed how nursing support extends to the relatives of the dying patient. It described the different ways that the nurses work with the relatives or the informal care giver and other healthcare providers in ensuring a safe and dignified death at home. It was established that after deciding the location of death of a patient it is the nurses' role to see the patient through to the final moment of the process of death.

The findings also described in detail the type of support that the nurses offer to the dying patient and how it leads to a dignified comfortable death for the said patient, in the following areas: Nurses' involvement in location of death, which included nurses' influence on family dynamics and the presence and availability of nurses; Nurses' facilitation of care where advocacy of nurses to patient and provision of safety by nurses was discussed; Managing nursing care under which was discussed nurses as caretakers and care coordinators as well as nurses empowering the families of dying patients and the final section, nursing support at the end of life within which relieving the symptoms of the dying patient and providing a dignified and comfortable death were discussed.

Nursing care is an integral part of home care for the dying patient, the support offered by the nurses ensures that the patient at home is cared for just as those in other institutions.

Keywords: Nursing support, dying patient, family, nursing care

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## 1 Introduction

Caring for a dying loved one isn't easy. Even when you know the end of life is approaching, you might not feel prepared. Understanding what to expect and what you can do to increase your loved one's comfort can help. Many people choose to die at home or in the home of a family member. There is a growing sentiment that care for the terminally ill be provided in the home setting if this is feasible. For many people, home is more than physical space; it represents familiarity, the presence of loved ones and the possibilities of enjoying "normal life". If given the option to choose, most people would choose to die at home surrounded by those who they love. (Munday, D., Petrova M, Dale J. 2009) to attain this, dying patients require support and resources to help them cope. Sometimes this can be burden to the primary health care team and relatives in terms of time needed and emotional feelings but it can also be very rewarding.

During recent years it has also become increasing common to care for terminally ill patients in their own homes and in community care facilities. For those patients wishing to die at home, there must be adequate backup of a person such a spouse, long- term partner, close relatives or team of health professionals who are available 24 hours a day. When nurses and other health care professionals are involved in the care of a dying patient, they are mostly encountering a person who is terminally ill. This means that the nurses caring for this patients should have the experience to give holistic care from physical, psychological, social and spiritual care for the patients and as well as the relatives during and after the time of illness. This nurse should have a positive attitude and be well acquainted with the care in the final stage of life; the care given to the patient is enhanced by nurses who are knowledgeable about end of life care (Dunn, Otten &Stephens, 2005).

The way the health professionals treat patients, the way they act toward the patients and the relatives is of such tremendous important because it can have such lasting effects both negative and positive. Emotional stress of caring for a dying person maybe overwhelming and frightening for both the dying persons and their families that is why families should get counselling by health professional to help alleviate problems by letting them know what to expect and reassuring them that appropriate assistance will be available if needed (Leahy, Fuzy, & Grafe, 2004)

## 2 Purpose of the study and research questions

The purpose of this review was to illustrate how current literature has described the support that nurses provide to the dying patient at home as well as his family.

The research question: How do the nurses provide support to the dying patient and his family at home?

## 3 Systematic literature review

The study was entirely carried out based on systematic qualitative literature review method. A literature review is a written summary of the state of existing knowledge on the research problem. It involves identification, selection, critical analysis and written description of the existing information on a topic (Polit and Beck, 2003 pg 111). According to Lobiondo-Wood and Haber (2002) qualitative literature review aims at bringing out information from previous researches on the same topic and explaining how they relate to each other. The value of evidence-based practice is becoming more and more apparent in the modern times, which has led to literature reviews continuously increasing their significance in the field of health and social care (Aveyard, 2007).

Literature review method was mainly chosen in order to identify all that was known about the topic, previously unanswered questions and the variations between the studies previously carried out in the area of interest. According to Tranfield and Starkey, (1998) literature review has increasingly become important in the health-care field as a result of the necessity for evidence based new methods of provision of healthcare, additionally, in order to improve nursing processes and practices, literature review is necessary for the synthesis and review of evidence based information, (Polit and Beck, 2003)

### 3.1 Data

#### 3.1.1 Literature search

The data search is aimed at finding relevant articles for the topic of research. The most important thing in carrying out a literature review is to ensure that the methodology section is well written so that other researchers would produce the same result given the instruction and the direction of the authors. Thus it is required to form a strategy of how to proceed with the literature review once it has started (Aveyard, 2007). The aim of data collection according to Aveyard, (2007) is to answer the research questions. However there is more than one answer to each question thus inclusion and exclusion criteria are formed in order to limit the number of articles that will be used. Additionally if any article matches all criteria and it is not used for the research then the reasons for its exclusion must be well explained. Using the keywords derived from the research questions and purpose statement, articles were searched from various data bases; the free national centre for biotechnology information (NCBI) was primarily used although the school library database was used through the Nelli portal which combines a number of databases. The full Boolean search method was applied in the search, where the key words were combined to come up with search phrases. This method was applied to narrow down the number of hits produced when each word was searched individually.

The table 1 below describes the literature search with the combination of the keywords to form search phrases and the hits that came up as well as the first inclusion and exclusion criteria. This first criteria that was applied, excluded all articles that were published before the year 2000 and included all those published in the year 2000 and thereafter.

Table 1 Search phrases and the number of hits

Database search	keyword	hits	Hits by inclusion
NCBI	Nursing support for dying patients	3082	262
NCBI	Nursing support for families of patients dying at home	2280	120
NCBI	Nursing support for dying patients at home	1150	98
NCBI	Dying at home	12222	213
NCBI	Nursing support for dying patients and their families	755	39
NCBI	Nursing care for patients dying at home	267	9
eNelli	Nursing support and dying patients	7500	215
eNelli	Care for dying patients at home	3644	99

### 3.1.2 Data screening

Screening data involves creating a criterion for which to include or exclude the articles collected in order to come up with a relevant working sample. In screening the data element of the data that were found relevant are noted and matched to the other articles to come up with reasons to include or exclude the articles. According to Burns and Grove (2001), the inclusion criteria refers to the characteristics an article has to meet in order to be used for the study, whereas the exclusion criteria is the characteristics of an article that make it unsuitable for the purpose of the study. Table 2 below is a representation of the inclusion and exclusion criteria used in the literature review.

Table 2 Inclusion and exclusion criteria

INCLUSION CRITERIA	EXCLUSION CRITERIA
Articles chosen were published between year 2000 and 2010	Articles published before the year 2000
Articles published in English Language	Articles published in languages other than English
Research articles that were relevant according to our purpose statement	Articles that were irrelevant to our purpose statement
Articles that provided a solution to our research question.	Articles that did not answer to our research question.
Articles that were researched and evidence based	Non evidence based articles
Full text articles	Non full text articles

The inclusion and exclusion criteria described above was applied to the search results represented on table 1, as shown in table 3 below. The columns represent the number of articles that were obtained after each inclusion and matching exclusion criterion were applied on the search produced articles

Table 3 Illustration of the application of the exclusion and inclusion criteria

Database search	keyword	hits	published after year 2000	Free full text articles	Evidence based articles
NCBI	Nursing support for dying patients	3082	262	97	8
NCBI	Nursing support for families of patients dying at home	2280	120	55	6

NCBI	Nursing support for dying patients at home	1150	98	22	5
NCBI	Dying at home	1222 2	213	61	5
NCBI	Nursing support for dying patients and their families	755	39	21	3
NCBI	Nursing care for patients dying at home	267	9	7	3
eNelli	Nursing support and dying patients	7500 5	215	58	4
eNelli	Care for dying patients at home	3644	99	42	5

Having applied these inclusions and exclusions there were 39 articles saved into the library personal work space; these articles were then examined in order to determine how well they answered the research question. In the final tally there were 12 articles that were deemed useful for this study. These articles are summarised alphabetically in appendix 1.

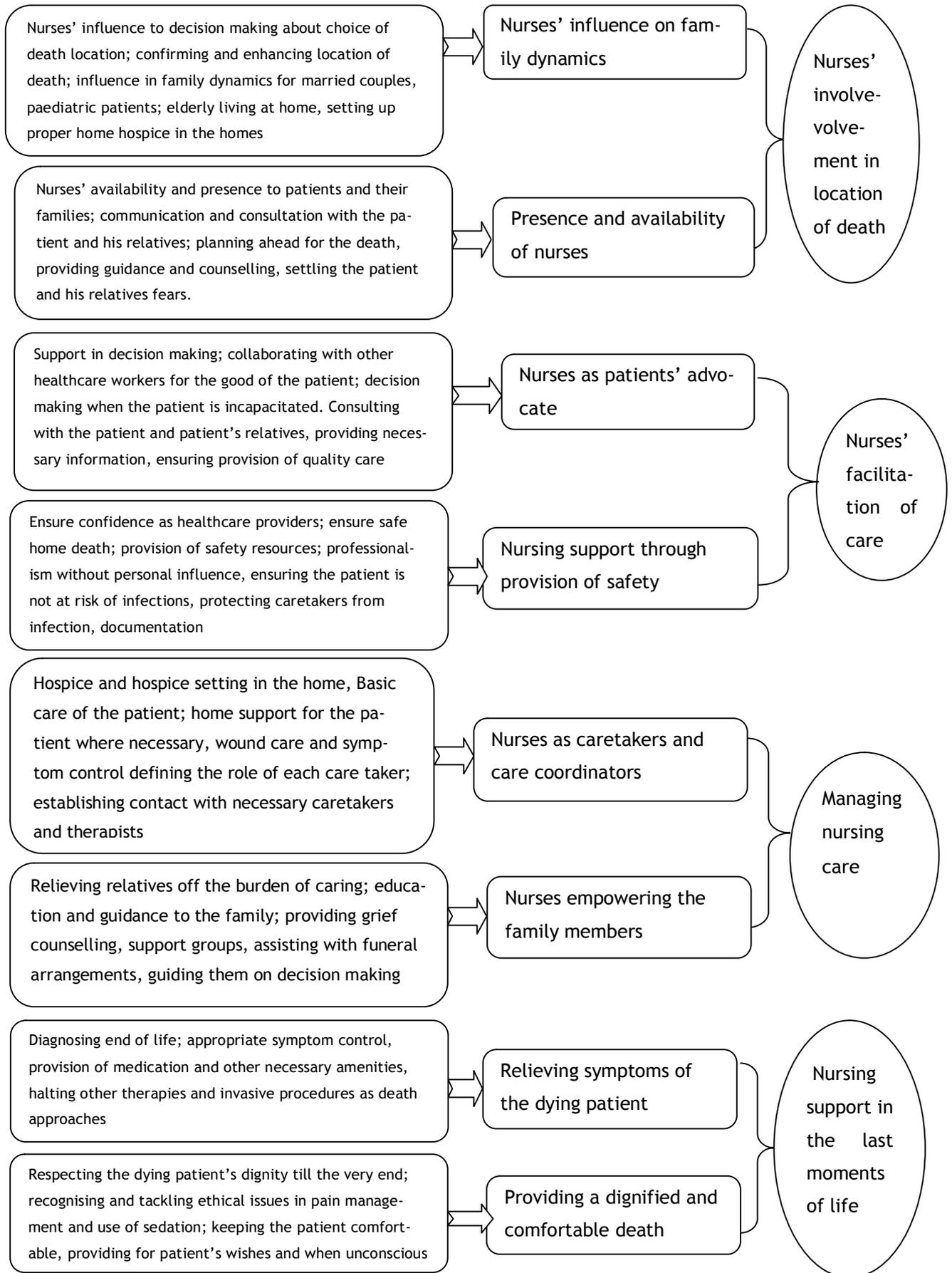
### 3.2 Data analysis

Qualitative Data Analysis is the range of processes and procedures whereby we move from the qualitative data that have been collected into some form of explanation, understanding and interpreting this data. The idea is to examine the meaningful and symbolic content of qualitative data. The main goal in analysis of qualitative data is to organize the gathered information to attain a conclusion and data conveyed in a research report (Polit & Hungler, 1995). Qualitative content analysis is a research technique used for objective, systematic and qualitative description of documentary evidence. (Lo-Biondo-Wood & Haber, 2006 p.559-575). Of the 12 analyzed articles, the relevant sources of information were the abstract, findings and discussion of the articles

As the meaning of data analysis is explained above, the first step of the analysis was systematically reading through all the articles more than once and relating them to the purpose statement and research question of this thesis. While reading through the articles phrases and sentences were developed relevant to the purpose statement and research question. Once this was done the next step was reading through the phrases and sentences. Sentences and phrases that were related were matched and grouped. From these related sentences and phrases a cover phrase that summed them up was developed. The related cover phrases were then synthesised and merged to form four interrelated nursing support areas that were then discussed and described individually in the findings chapter.

To give an example of how the first nursing support area was developed: nurses' involvement in location of death; the articles were read through and sentences and phrases relevant to the research questions were developed. The following phrases were picked up from different sentences and deemed to be related: nurses' influence to decision making; confirming and enhancing location of death; family dynamics. These were grouped and given a cover title: nursing influence to family dynamics. The same was done for the next set of related phrases: Nurses' availability and presence to patients and their families; communication and consultation with the patient and his relatives; planning ahead for the death, which were grouped and a cover title developed as presence and availability of nurses. The two cover phrases were then merged to form the first area of discussion as nurses' involvement in location of death. This process was repeated to form the other three areas discussed in the findings chapter.

Figure 1 Illustration of data analysis process



## 4 Findings

In this chapter, the evidence gathered as answer to the research question from the analysis of the data that was gathered, was discussed in depth. Four key areas were identified namely: nurses' involvement in location of death; nurses' facilitation of care; regulation and managing nursing care and nursing support in the last moments of life.

### 4.1 Nurses' involvement in location of death

As healthcare providers nurses are charged with the responsibility of looking out for the patient needs as long as the patient is in their care. The nurses provide an unbiased opinion of what decisions should be made based on the available facts. The accessibility of the nurse is also a source of comfort for the patient.

#### 4.1.1 Nurses' influence on family dynamics

Once a patient is suffering from a terminal disease and it has been decided that the cure is not working the next step is to discuss with the patients about their option once their condition begins to deteriorate. This is never an easy step for the patient as well as his family. In such circumstances patients are faced with varying emotions and choices since their lifetime suddenly become limited to a couple of months, weeks or worse days. For such patients it is recommended that they be introduced to palliative care which can be done in many various ways. With the help of the family to make the decision about where they wish to die, this could be within the hospital where they may feel well cared for and they would wish to stay there till the end of their life. Some patients would want to go to a hospice facility to stay with other dying people especially if they do not want to stay in the hospital and they do not have the possibility of staying at home with their families. Some patients choose to go home to be with their family just until they die. Usually these are people who together with their family have already anticipated going home after hospitalisation whether they are healed or not. The kind of palliative care provided in the home setting is known as home palliative care.

As discussed above, it is at the patient's discretion to choose the location of death most preferred. Where patients choose to die in their homes various factors are

geared towards this decision. The reviewers found that many people that choose to die at home the choice is further fortified by the presence and availability of home-care within their homes. Family dynamics apply to three categories of families; married couples, paediatric patients, old people with close family support.

Prior studies have shown that in the case of a married couple where the ill partner has been living within the home before their illness and in between hospitalisation periods it is necessary for them to keep the family dynamics in place even when they are faced with the fact that one of them is about to die. The choice for them is usually for the ill spouse to be at home pending their death arguing that they will spend more time together. The reviewers found that as much as it was quite a burden for the healthy spouse to take care of the dying patient especially where there is disability from the illness, however the healthy relative was still willing to do so and was successful in caring for their loved ones with help from the health care practitioners. For those couples that have been together through various phases of life it seems like the obvious thing to do for the dying spouse. The reviewers found out that taking care of marriage partners gives some kind of satisfaction to the healthy relative about having done everything possible under the given circumstances. Additionally by being within the home the couples are able to be the major decision makers of the care that is going to take place they are able to jointly make the choices that make the end of life transition easier on the couple.

In the case of paediatric patients they are found to be the best candidates of home palliative care. This is because until recently when paediatric palliative care was introduced in many places the choice was for either paediatric patients to die in the home or in hospitals. Many families prefer to have the young patient die in their own homes so that they can have them at home for one last time. Moreover the children would always rather go home and be with their families than be in the hospitals. A study carried out in Italy showed that having the child die at home helped the parents with the grieving process because they got their last wishes for their child. The same study showed that when parents agreed to take the child home and do away with the invasive treatment the child's dying moments were much more peaceful and parents felt that they had done the right thing by their dying child. In addition the family dynamics and structure is maintained by having the whole family together in one place rather than having the constant visits back and forth to the hospitals as is the case where the children are hospitalised until they die, this is especially true for families that have a dying child and siblings to that child.

Family dynamics and family structure also apply to the families where the elderly still live with the rest of the family or at home with the help of relatives. When faced with death this group of people are used to certain way of life away from the hospitals or hospital like institutions, therefore where it is deemed that with the support system they have the patient can be well taken care of at home through home hospice thus can have their wish of dying at home. An exemplar of a professional health care practitioner taking care of her dying father at his home with the help of her sisters showed that the whole family with the help of the community nurses were able to give the dying man the kind of death he considered dignified. This exemplar showed the possibility of having a home death for a person who has been living alone but has been rendered helpless by illness. The role of the community nurses in conjunction with the help from the relatives of the dying patient are paramount to providing quality home deaths to any client who wishes so.

#### 4.1.2 Presence and availability of nurses

Apart from the patient and his family, the choice of location of death can be influenced by the health care practitioners. The community nurses can seal the decision made by the patient to stay at home and die there. The community nurses with good relationship with the patient make it easier for the patient to want to stay at home since they will be getting constant care from the people they are familiar with till the time they die. In fact where the patients and the nurses have been discussing the effect of the end of life choices by the patients this influence is greater and the patients tend to want to remain in the care of healthcare practitioners they trust most, this is especially so when they are faced with imminent death and they want to feel well taken care of. Studies suggest that the foundation of a good home death is the support that will be given by the nurses. Thus if the nurses do not see the possibility of the patient being able to cope at home especially in cases where the disease has progressed rapidly and the care at home lacks for all the necessary facilities. In such situations as much as the patient would like to die in the home the nurses are forced to disagree and find another place, which could also be a primary care setting where the relatives can still participate in the care of the dying patients.

In addition the community nurses have a role to influence and enhance the planning of the death in the home. By organising visits by the priests where the patient and the relatives deem it necessary then they ensure that the relatives do not have to deal with

the most difficult of end of life decisions. In addition the nurses discuss with the patient and his relatives about death in order to relieve their fears and reservations about death so that they are able to let go freely. Failure to do so will lead to the patient hanging on longer and lengthening the suffering of the dying person. Moreover by discussing about death with the relatives they could also make funeral arrangements and include the wishes of the dying patient if he is in any condition to pass them on. Studies have shown that especially for paediatric patients, making funeral arrangements before they die can be a form of cleansing for the parents who are about to lose a child. It makes it easier for them to let go since it is a way of accepting the inevitable.

#### 4.2 Nurses' facilitation of care

Patient advocacy and provision of care safely are the fundamental focus of proper nursing care. The nurses are obligated to ensure that all decisions made in their presence are for the good of the patient. Where unfavourable decisions have to be made the nurse has the duty to explain to the patient clearly the necessity of such choices. Patient safety centres on provision of care with the patient as the priority and ensuring no harm or danger comes to the patient.

##### 4.2.1 Nurses as patients' advocate

By virtue of being a healthcare professional, the nurse is to the patient the voice of reason and an educated perspective to issues they may have to deal with. In this way the community nurse provides solutions and answers to problems and questions that trouble the patient in regard to their daily life, treatment and care. Advocating for the patient is a requirement according to the ethical guidelines of nursing care. It is a fundamental requirement for every aspect of care, that the nurse does only those things that are most beneficial to the patient and avoid any harm from occurring to the patient the nurse is in charge of. Advocacy is the aspect of nursing care that requires the nurse to know the choices that the patient would want made when they do not themselves have the capacity to make them and enforce them on behalf of the patient.

Where in the healthcare team decisions about the patient have to be made, the nurses can prevent harmful or insufficient measures from being applied for the good of the patient. In situations where there is a dilemma the nurse can influence the decision

so that the best choice is made or a concession between the available solutions is reached. Moreover, where the patient and his family members need to make a decision as regards to the need for a certain therapy or procedure, the nurse has the obligation to fully explain the need of the procedure or therapy. Thereafter the nurse needs to explain the reasons to have and those not to have the procedure done as well as any side effects involved. Where possible the nurse should present case studies or statistics to help the patient make the best possible solution. There may also be the need for the nurse to offer his own opinion while ensuring that the patient does not feel forced into any decisions.

Additionally the nurses reinforce the choices they regard as being most suitable for the patient while still allowing the patient the autonomy of making the decision themselves. Studies show that where the patient have trust and respect for the home care nurses looking after them they are more comfortable with the decisions they make and are more ready to discuss them with the said nurses. The nurse being the go between for the patient and other team members of the hospice care plays the role of an advocate to the patient. The community nurses thus make the decisions that will be most beneficial to the patient. They also consult with the other team members as to the way they will coordinate the care provided to the patient. Once the doctor has prescribed medication to the patient it is the duty of the nurses to administer such medication to the patient or where possible educate the patient on how to do it by themselves if they are capable. As an advocate of the patient the nurses are also responsible for clarifying the things that the doctors and other professional team members have discussed about the care of the patient, by simplifying the language used in the said discussions.

#### 4.2.2 Nursing support through provision of safety

Community nurses in providing home hospice to the dying patient are charged with the responsibility to provide safety in the home and assurance to both the patient and his family members. Provision of safety takes many dimensions that will be explained in the following subtopic. For starters, the nurses have to ensure the safety of the patient in the following ways: provision of a hospital cot and mattresses suited for the terminal care patient to ensure that the patient is comfortable and they are able to be cared for without injury to the carer; provision of safe ways to care for wounds alleviating the

pain of the patient as well as caring for the wounds regularly to prevent further infection; allow the patient to make decisions about their care whilst they still can and when the patient has given advance directives these too need be considered in the decision making process; record daily event and keep proper documentation of the care of the patient to ensure that all that needs to be done is done and done well. Studies conducted by the international council of nurses have shown that lack of proper documentation of nursing processes is by itself a leading cause of poor nursing care. It leads to the disruption of the chain of care from one nurse to the next, moreover it is impossible to tell what the other nurse has done unless they are both present at the same time.

The nurses also provide safety for the care takers by provision of protective clothing to minimise the risk of infection from and to the patient. The risk of infection for dying patient is quite high since their immunity is already compromised by the disease suffered. It is therefore paramount to ensure that there is no risk for further infection, which can easily be done by ensuring asepsis when caring for the patient. The caretakers need to be provided with gloves masks and other necessary protective clothing for the care of the patient. On the other hand in some other cases the patient carries an infectious disease which the caretakers are prone to. Then the nurses have the responsibility of ensuring that the caretakers do not contract the infection from the patient by applying protective measures. By educating the caretakers and the patient on procedures to use in the provision of terminal care, the nurses ensure safe provision of care for the dying patient.

The nurses need to assure safety for the dying patient while providing home hospice care by carrying on their duties without personal influence. As nursing professionals the nurses have a duty to the patient and the ethical and moral board to ensure that they provide care without any bias. Many studies have reflected that nurses in most cases do not let their personal issues affect their quality of work; in addition nurses provide proper care even when the circumstances affect them in one way or another. However, community nurses are more prone to such bias since their place of work is outside proper designated care areas such as hospitals or nursing homes. It has been noted in some studies that community nurses are more likely to suffer violence from patients than nurses working at the hospitals. This makes them more vulnerable, although the studies show that even with such circumstances the nurses still endeavour to provide proper care for their patients as much as possible.

The effect of the nursing care provided goes to ensure that the hospice care provided ultimately leads to a quality home death. Quality home death is ensured when the care that is provided is well coordinated and holistically centred on the client in this case the dying patient. The community nurses by providing the information about the necessity of certain measures both invasive and those meant to keep the patient comfortable create the necessary balance between what the patient and the family wants and what is actually necessary. Studies have shown that the effect of good nursing care is the key to improving the quality of home deaths. A study carried out in the United States showed that where there was a lack of an active doctor, nursing care made up in reassuring the patients and keeping them on the loop of how they were progressing. It also gave them a sense of being taken care of that every person needs from their health care professionals.

### 4.3 Managing nursing care

Home hospice care is provided by a large number of people namely: nurses, doctors, therapists, grief counsellors, informal caregivers such as the family members, and in some cases religious ministers. Therefore it is necessary to manage the care process by ensuring that all parties adhere to their duties and do not interfere with nursing care. The nurse are charged with the responsibility of regulation and management of care since they are the professionals with the most contact with the patients

#### 4.3.1 Nurses as caretakers and care coordinators

Hospice care is the provision of palliative care to terminally ill patients, who no longer seek treatments to cure them. Palliative care by definition is the care provides aimed at improving the overall quality of life that is provided to any patient facing serious illness. It is provided by a team of professionals with the emphasis being placed on intensive communication, pain and symptom management and coordination of care. Palliative care is provided by a team involving healthcare professionals. It focuses on the holistic care of the individual patients and it is tailored to the needs of each patient specifically. Palliative care is not limited to hospice care in the sense that palliative care can be provided to the patient at any time in the course of their illness from the time of diagnosis

and it can take place at the same time as curative treatment. Palliative care when administered properly has the following benefits to the patients: close, clear communication; expert management of pain and other symptoms; help in navigating the healthcare system; guidance with difficult and complex treatment choices and emotional and spiritual support for both the patients and the family

Home hospice is the provision of hospice palliative care in the home or a home like situation. It involves the liaison between palliative care and home care where the location of the care is in the patient's home. A study showed that taking care of patients in their home gives them a sense of control in a situation where they lack control of. These patients would rather be in their safe place which in this case is the home. The home care is provided by a team of dedicated professionals who bring their expertise on a scheduled visit to the patient's home. Depending with the needs of the patient the care provided can be structured in various ways. The nurse visits are usually at least once daily while the doctors visit could be once a week to a maximum of twice daily. The team of professionals also includes regularly consulting nutrition therapists, psychotherapists, physiotherapist and priests. These professionals work in conjunction with the relatives of the ill patient to provide as ideal as possible palliative care in their own home. The role of the nurse is one of most important element in implementing a good home hospice care situation. The nurse has a duty to the terminally ill patient, to the family members of the dying patient and overall there is an effect to the support provided to them.

Studies that were reviewed showed that nurses play a major role in defining the palliative care that will be provided to the patients. Nurses are the major link between the patient and his family and the healthcare and other professionals that are involved in the hospice care of a patient. This is especially true in the home hospice situation where the only professional in most cases that visits on a daily basis is the nurses. Community nurses or home care nurses are the nurses that are involved in the care of patients at their homes. The role of the community nurse to the terminally ill patient revolves on a large scope. These community nurses are involved in the care of the activities of daily life. For starters the nurse is the facilitator of care at the home; this means that the nurse takes care of the daily needs of the patient including assisting where needed with washing, feeding and elimination. The nurses also gives education and guidance on how to take care of themselves, especially in situation where the skin ails from invasive punctures or bed sores and the care of these is necessary to increase comfort and reduce pain.

#### 4.3.2 Nurses empowering the family members

To the family members of the patient the nurse's role is quite significant as well. First of the nurse acts as the planner and care coordinator for the patient's care, it is the nurses role to provide instruction on care to the family members responsible for the care of the patient. The nurse can also assist in the making of tough treatment decisions as well as coordinate visits by other professionals on behalf of the patient and the relatives this is especially so for the patient who cannot make decisions for themselves such as children or incapacitated elderly people. Secondly the nurses have the role of care assistant in the home, thus relieving the relatives off their caring duties even if it is for a short while. Moreover they help the relatives through education guidance and communication. The guidance is so that they home care does not lack of the services provided in other palliative settings. They educate so that the care takers at home feel equipped enough to take care of the people they love without any errors. They also educate on how to administer pain medication and the use of other therapeutic measure to keep the patient comfortable in the absence of a nurse. They also give them a list of signs to look for to determine how the patient is feeling when the patient is not responsive. The nurses also arrange for grief professionals for the relatives to aid them in the coping of their loved ones illness and their death after the death has already occurred.

Death is a journey; it is the process by which the functions of our body shut down one after another until the body can function no more. Since it is the final phase of life most people would rather share this experience with their loved ones, thus the choice by many to die in their own homes with their family and friends present. This is especially true for the terminally ill who before their illness have been living at home. The family and the dying person having made this choice understand the requirements for a 'good' home death. The nurses and other health care workers endeavour to make every location of death medically sufficient. The benefits that result from choice of home location are as follows: home is where the patient feels more peaceful and comfortable; sharing lasts moments with the family as a part of it rather than getting regular visits at the hospital; allowing the family and the relatives one more chance to be part of their daily lives as death approaches; the relatives and family of the dying patient feel more involved in the caring and decision making of end of life issues; home hospice gives the family and the dying patient a

spiritual connectedness and allows for care with security since the hospice team is always just a phone call away.

The community nurses role to the relatives of the dying patient stretch till after the actual death has occurred. The nurses may assist in funeral arrangements by getting the family in touch with the necessary authorities. This is especially in the case where the family members are too distraught by the occurrence of the death, which studies have shown to be the case in most paediatric home death cases. Additionally the nurses can organise grief counsellors for the relatives after the death has occurred to help them cope and death with the grieving process, other than that the nurses could arrange for the bereaved relatives to meet up with other families and individuals who have experienced the same situation or organise support groups for bereaved people.

#### 4.4 Nursing support in the last moments of life

In order to provide all the necessary care and support that is needed at the end of life, the onset of dying need be recognised. Not only does it mean that there should be effective symptom control, but also the necessary communication between the patient and his relatives as well as to the health care providers need to be provided for. Apart from these there needs to be a consideration for the provision for ethical issues that are key end of life issue. In this section the reviewers discuss the end of life issues in home deaths, how they can be alleviated and their impact on the quality of death.

##### 4.4.1 Relieving symptoms of the dying patient

The end of life issues in home deaths are: how to diagnose home death; appropriate treatment at the end of life; key symptoms in dying and ethical issues at the end of life. Diagnosing death is important in ensuring that treatment is tailored to the patient appropriately and also make the patient aware and empowered to make the choices about the management of the last phase of their lives. Studies have shown that health care professionals consistently overestimate the survival of the patient and familiarity with the patient has been shown to increase the chances of this

happening. As much as there are clear symptoms that death is about to occur it does not happen in all cases and as much as half of the deaths that occur in the homes are symptom less, according to a study carried out in the Netherlands. However, almost all patients according to the studies reviewed had diminished consciousness 24 hours prior to death. Another study revealed that a person has a mean of two days to live if two out of the four signs below are present: bedridden suddenly; semi comatose; only able to take sips of fluid and no longer able to swallow tablets

Once the end of life has been diagnosed it is time to give the appropriate treatment at the end of life. This involves more than giving the right drugs in the right amounts to the dying patient. The patient's end of life declarations are followed since as death nears the patient is not able to make decisions on his own. The health care team is usually available and on call 24 hours a day. But even with them the role of the informal caregivers is most important and they must have nursing equipment available in the home to increase the quality of death at home. It is vital to have more than one informal care givers that are dedicated to the care of the dying patient otherwise the home death possibility becomes a burden to an individual. Further treatment, if at all was going on in the home, needs to be stopped once the onset of death has been diagnosed. Other therapies that become irrelevant should also be stopped at this stage and the concentration is kept upon relieving the key symptoms in dying.

The key symptoms in dying include pain, breathlessness, secretions and restlessness. Pain contrary to belief can be reduced and has been known not to dramatically increase towards the end of life. In fact, it tends to diminish in the last weeks and days. However since those close to patients fear that there will be an increase in pain the provision of adequate analgesia has to be ensured close to dying. Since swallowing becomes hard on the patient the use of oral medication is changed to parenteral route of administration. Additional drowsiness is to be expected where there is renal failure due to the lack of elimination of opioids metabolites. Another symptom at the end of life is breathlessness, it however does not necessarily a sign of lack of oxygen and so does not call for immediate initiation of oxygen therapy. Opioids offer some small amount of relief for breathlessness. Benzodiazepines that provide relief from agitation may be beneficial in catering for this symptom by means of their muscle relaxing properties.

Secretions is the other key symptom it is caused by the inability to cough up airway secretions and they thus collect and cause a rattling sound when the air bubbles go through them. It is not uncomfortable to the patient but rather unnerving to the relatives that take care of the patient in the home. A proper explanation as to the reason for the occurrence of the sound and reassuring them that it is not caused by congestion will be enough to satisfy the caretakers. The addition of an anti cholinergic agent reduces most cases of the secretion problem. The final key symptom is restlessness, which may be due to pain as well as anxiety; it has to be distinguished from the frequent focal myoclonic jerks that occur in patients in the last days of their lives. Opioids should not be used alone to control restlessness but rather the use of benzodiazepines either alone or the use of the two together. Acute confusion may also be the cause of the restlessness to the patients. In taking care of the agitation it is necessary to ensure that the patient is not suffering from opioids toxicity by assessing the amount of opioids given to the patient. Opioids use has been an ethical hagggle point for dying patients especially when it results in toxicity and this is not diagnosed in time.

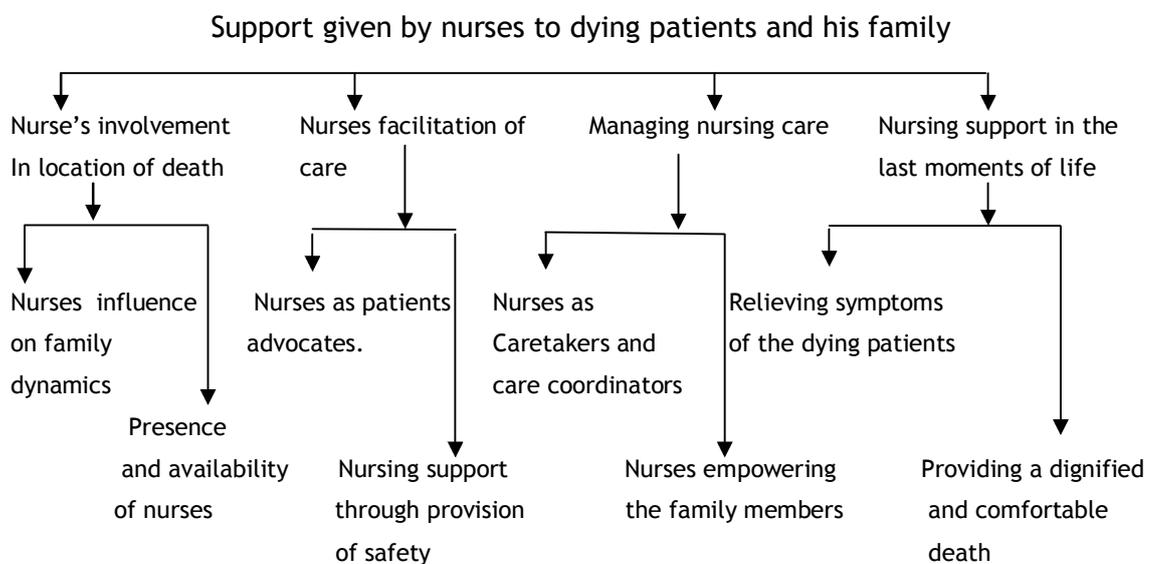
#### 4.4.2 Providing a dignified and comfortable death

According to a study by the world health organisation, end of life care appears to be fraught with ethical issues; this is in part due to the legalisation of euthanasia in some western countries. The most important is the symptom control without shortening life. This is arguably the most ethically challenged issue since symptom control is necessary and the shortening of life is both ethically and morally incorrect. In this case the intention is what counts; a healthcare practitioner may be sued for symptom control if their intention was more to shorten the life of the dying patient than to control the said symptoms. Use of sedation appears to be the other contentious ethical issues. The necessity of sedation has been established in prior studies but it is possible to kill people with sedatives however it may be necessary as a symptom control in the last days of life. There are raised concerns that in some cases the sedation may be used as a cover for euthanasia. A study has been carried out to show that agitation and restlessness can be controlled in other ways than with the use of sedatives. When deciding the use of sedation for a patient the relatives involved in taking care of the patient should be consulted and where possible consult the dying patient too.

The sedation should be achieved by use of sedatives to decrease the chances of intoxication, which are usually raised when sedation is achieved by the use of opioids.

Another ethical issue that the nurses need to deal with is to allow the patient to be autonomous up until the end of their lives. Studies have shown that in some cases due to heavy work load the nurses may tend to neglect the dying patient in favour of those who are much better. The dying patient just like any other deserves the same kind of care as any other. The nurses should not in any case neglect to carry out all necessary procedures just because the patient is about to die. Terminal care should be done in such a way that the patient's needs and dignity are observed. Where the patient is lucid enough to give instructions, their instructions should be followed as much as possible. Where the patient has before losing consciousness gives express instructions in writing or verbally to the nurses or to the relatives, or in cases where there exists the dying patient's advance directive, these instructions should be followed just as if they were verbal by providing the nursing care as per the patient's wishes. Another ethical pointer is allowing the dying patient's appointed power of attorney to make decisions on behalf of the patient. It is also necessary to consult such a person in case where consultation should have been sought from the patient. This apart from being beneficial to the patient prevents the possibility of law suits to the nurses involved in the care.

Figure 2: Summary of the Findings



## 5 Discussion

### 5.1 Ethical Considerations

Defining the research topic and the research questions as well as providing support information as to the necessity of the study leads to issues that can be challenging. This thesis was carried out under Safe home project of the active life village. The project aims to come up with innovative ideas which will help the aging generation to remain in their own homes as long as possible and make home a safe place for them. The tutors provided thesis idea and enough information about what should be included when conducting this study. There was no financial support offered for the purpose of this review.

Systematic literature review is the method that was used to conduct this study. The authors got permission from the tutors who are the supervisors of this paper and the authors followed Laurea University of Applied sciences thesis guidelines when writing this thesis. Accuracy was one of the ethical considerations that were taken into account during data collection and data analysis. All articles used were accurately reported to avoid deviation from the truth. Direct quotations were accurately noted and accounted for by using correct referencing according to Laurea's thesis guidelines, proper accreditation was given to the authors of the articles and publication. To maintain proper accreditation, quotation was properly done as it was in the text. Accreditation has been shown by creating a list of references; this gives evidence to the reader. The lack of accreditation in the findings section of this thesis is due to the fact that the findings are solely the interpretation of the reviewers of the articles analysed, therefore, does not reflect on the opinion of the authors of the articles used in the review.

## 5.2 Trustworthiness

Trustworthiness of a research is to assure that credibility; dependability; conformability and transferability have been evaluated and put into consideration (Talbot, 1995). Trustworthiness in this study was attained by excluding unwanted results and unnecessary data. According to Lobiondo-Wood & Haber (2006), it is advisable to assure that trustworthiness in qualitative research had been observed with great care.

The most important thing in carrying out a literature review is to ensure that the methodology section is well written so that other researchers would produce the same result given the instruction and the direction of the authors. Thus it is required to form a strategy of how to proceed with the literature review once it has started (Aveyard, 2007).

To ensure that credibility was maintained in the study, the facts are detailed and reviewed by the supervisors to ensure that the facts have not been misconstrued in the interpretation and conclusion of the reviewers (Talbot, 1995).

Secondly in ensuring transferability it is important to detail the process that was used to come up with the findings from the data that was collected. Therefore, using the same process and resources other researchers could come to the same conclusions i.e. the study is repetitive. It is possible to repeat the research. In this study the quality of research was examined by showing how the data was analysed and interpreted.

The goal of research, as defined by Burns and Groves (2005 p.203), is to generate rigorous scientific knowledge. Therefore, for a scientific research to be ethically acceptable with credible findings, a good scientific conduct is required. Honesty, integrity and accuracy of the research process must be guaranteed when reviewing and reporting research studies. It also requires that the data collection, research and evaluation methods conform to scientific criteria, avoiding research misconduct (including fabrication, falsification and plagiarism). The reviewed sources and their authors must be respected and accurately referenced (Burns & Groves 2005 p.207)

### 5.3 Discussion of findings

The purpose of this review was to illustrate how current literature has described the support that nurses provide to the dying patient at home as well as their family. To enable any person willing to die at home have that possibility regardless of the medical and nursing care that may be necessary and seemingly impossible to provide within the home. This thesis is aimed at being available to home hospice carers and supporters to show how the home death can be made possible for all those that require it to be. (Sexton & Munro, 1988)

The focus of nursing care is the patient who is terminally ill, approaching end of life and would like to consider the possibility of dying at home surrounded by his relatives. The main issue discussed was how well the nurses are able to provide palliative care at home. According to Johnston & Smith (2006) confidence in the health care providers is the main element the patient and the relatives consider for a safe home death. In regards to home death, the nurses need to be available to the satisfaction of the dying patient as well as the relatives that are involved in the care at home. The dying patient and the relatives need to have confidence from the nurses and other professional carers who are involved. When the patient gain confidence of the nurses they are assured of an adequate back up 24 hours a day. This eases emotional and physical burden for both the patient and the relatives which at this stage can be demanding. The nurses should be able to provide support and resources which will help the patient and the relatives cope at home. Nurses should have positive attitudes towards death and should be willing to perform their duties even when the circumstance is not ideally what they would hope for, (Dunn, Otten, & Stephens, 2005).

It is not all terminally ill patients that choose to die at home but for those who chose to do it they must be catered just as well as those that chose to die in an institution (Van der Heide, 2007). The complex natures of location of death require nurses to talk about it expressly with the dying patient. Once the choice of location of death has been made, it is the duty of the nurses to ensure that all that can be done is done to enhance the preferred location of death (Munday, Petrova & Dale, 2009). Home deaths are limited if the there is no availability of care is not available and this is one of the reason why a patient may choose another location to reduce the burden to their families.

As McCabe, Timmins & Campling, (2006) suggests if given an option most people would choose to die at home surrounded by those whom they love. But this option is not always possible if there is no availability of care. For the patient wishing to die at home there must be adequate support, this usually means a close person such as a spouse, long-term partner, close relative or a team who are available 24 hours a day. The family members must be prepared to cope with both the emotional and physical needs of the patient and these can both be very demanding because the caring role needs to be shared between the family members and the nurses. The nurses should ensure that the role of the family members in the care needs of the dying patient is well defined and maintained.

The nurses are the key workers who are the main contact for the dying patient, the family members and the rest of the healthcare team. Kendall, (1998) points out that the nurses are often not the most senior member of the team but rather the important in the team who liaise and who ascertain that nothing is left undone or duplicated. For the nurses to be able to provide end of life care they should have professional skills which will enable them to support dying patients who chooses to die at home surrounded with their family, friends and relatives. If the patient makes a decision to die at home, nurses should take into consideration of some of the things that the patient requires in order to make the death as comfortable as possible (Page & Czuba, 1999).

The nurses should have knowledge of holistic care for the patient in home hospice care. The nurses should make the family understand the need for peaceful and painless end of life transition using the necessary interventions, also keeping the family aware of different transitions of care. When the nurses have the ability to work together with the dying patient and the family members this is mostly considered of great importance because the nurses should be able to provide necessary information to the family members when planning the end of care. If the nurses have confidence, the family members as well as the dying patient will have confidence in them and this ensures quality of home deaths and efficiency of services provided (Marco et al, 2005). If the dying patient had any wishes concerning the end of life care this should also be discussed to in order to be able to make choices about how this will be managed.

In cases where the patient has been living with the spouse it is advisable that the spouse is in good health status and in the age where he/she is able to care for the dying partner. Sometimes the nurses may need to instruct the relative on how to administer some medication in a timely manner. If the patient is a child, most of the time the parents are the ones who make the decisions on behalf of the child. The nurses should ensure that children rights are followed and it is the role of the nurse to act as an advocate on behalf of the child. The decisions made should in the favour of the child. Nurse should ensure that the child and the parents all get the total support as it is needed.

Another key point is that, it is advisable for the nurses to have skills relating to communication with the children. Effective communications help the nurses have the right approach to the care and they should be able to reduce fear, isolation and helplessness through effective communication and proper discussion. Sometimes the nurses can help the parent in planning ahead for a child's death, this will help the family members to accept the death, when the death is planned at home and the parents are able to see it happen the way they had planned. It is important for nurses to educate and counsel the patient and family in order to facilitate the decision making, the patient for as long they are lucid and through appointment of a power of attorney, should have the final say in decision making.

Nurses' goal is to make the patient feel as good as possible and get the best possible home care at the end of his life in order to provide a good home death. It is mainly a huge responsibility for the nurses when they are caring for a dying patient, the way the patient and family members are treated and also the environment in which the patient will be allowed to die is of great importance because the way the nurses' act towards the dying patient have a long lasting effect. The ability for the nurses to work together with the dying patient and the family members is considered of great importance in order to be able to attain the goal of a good death; nurses should always be ready and able to provide the needed support and information needed through effective communication. Many people faced with death will turn to God either for the first time or as a return to lost faith (Gomes & Higginson, 2006) Patients and families should be put in contact with a minister of religion if required. Some patients may also wish to make peace to end grudges with relatives or friends.

Nurses need to be honest with the patient and answer questions to the best of their ability, including being honest about uncertainties. Most people do want straight answers but nurses need the greatest intuition to know just how much the dying patient really wants to know and how much he really wants hidden that is why as discussed earlier nurses need to have knowledge of effective communication with the dying patient and family members. Nurses' ambitions are to fulfil the wishes of the patients and relatives based on the needs that arise (Clark & Seymour, 1999). It is expected from the nurses to give good care at the end of life, the patient at this stage requires attention and good symptom control. In palliative home care, nurses need to further knowledge about the management of pain and distress in terminal care. Nurses should have positive attitude and they should also be well acquainted with the care in the final stages of life of the patient.

As the death approaches the patient will become weaker, and the level of pain may increase and lack of appetite. Palliative home care nurses need to have further knowledge about the management of pain and the family should be informed if the patient have reached a critical stage and if the nurses and other health professional team have made the decision on what routine of drugs need to be stopped. Structural changes, economic restrains in care as well as the organisational factors are the factors that influence the nurses' possibilities into meeting the needs of the patient and family members.

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## Appendices

## Appendices 1 Analysis of reviewed articles

Author and year of publication	Publication of article	Purpose	Method of data collection and participants	Central findings	Relevance of article to our thesis
Benini, Spizzichino, Trapanotto & Ferrante - 2008	Italian Journal of Paediatrics	Description of the need for palliative care for paediatric patients with terminal illness	The researchers analysed four models applied in paediatric care 2 institutional based and two home care based models	A detailed description of the challenges needs and legal issues that result from the care of paediatric patients and how each of them should be handled.	Paediatric patients are the best candidates for home care based palliative care because of the need for families to be with their children till the end of their lives. The information provides a way to set up a working model for caring for dying paediatric patients at home.
Callahan - 2005	Sage Publications	To describe the challenges of caring for a dying father in the home with the resources of a home hospice	Exemplar describing the experience of a nurse and her sisters in caring for their dying father.	Holistic care for the patient in home hospice care. Making the family understand the need for peaceful and painless end of life transition using the necessary interven-	Allowing the family and the patients for those who wish to have a chance for a dignified and utmost comfortable death in the place they spent most of their lives that is their homes.

				tions. Also keeping the family aware of the homecare available to them during this time.	
Carlson, Morrison, Holford & Bradley-	Health re-search and educated trust	To describe the services that the patients and their family members receive as palliative care.	Interviews to hospice staff most familiar with the patient and use of medical records to obtain data. Observational cross sectional study carried out from 1992 to 2000	There was a marked variation in hospice services provides across the sample. Out of five category checked for a third of the hospices provided only one or two and only 14 percent provided all the five categories of services	Understanding the impact of the services provided will to a greater extent provide the necessary incentive to provide good palliative care to the dying patient and his family where the setting of the hospice is in the home.

Dunn, Otten and Stephens-2005	Oncology Nursing Forum	To examine the relationship among demographic variables and the attitudes of nurses towards death and caring for dying patients.	Completed survey of three measurement tools: demographic survey, Frommlet attitudes towards the care of the dying and death attitude profile - revised	Nurses that participate had positive attitudes towards dying. Additionally regardless of how the nurses felt about death it did not affect the way they cared for their dying patients.	This information shows how well nurses can perform their duties even when the circumstances are not ideally what they would hope for.
Dussel, Kreicbergs, Watterson, Moore, Turner, Weeks & Wolfe-2009	Journal of pain and symptom management	To analyse the determinant of the location of death for a child	Retrospective cross sectional survey of bereaved parents. Use of questionnaires to gather data that was used in the analysis participants were bereaved parents	Type of disease and the child's characteristics, parent's characteristics and modifiable clinical factors determine the location of a child's death. Prior studies suggest there being beneficial effects to planning the death of a child at home. Its beneficial to plan also less invasive care at	Planning ahead for a child's death will help the family accept the death, when the death is planned at home and the parents are able to see it happen the way they had planned.

				the end	
Gomes and Higginson-2006	Bio-medical Journal (BMJ)	To determine the influence of different factors on place of death in patients with cancer	Qualitative literature review of articles searched from four databases. A conceptual model of place of death and its determinant was developed for the purpose of analysis.	There was heterogeneity between studies analysed. A list of factors, such as the illness, individual and socio economic factors, that determine the location of death and the provision of each to enhance the quality of death in the location chosen by the patients	This information provides a list of factors that must be considered in home care palliative setting for their provision by home care practitioners. Education to the relatives as well as home care practitioners should be done where a patient leans towards death at home.
Heyland, Dodek, Rocker, Groll, Gafri, Pichora, Shortt, Tranmer, Lazar, Kusto-	Canadian Medical Association Journal (CMAJ)	To describe what seriously ill patients and their families consider to be key element of quality end of life care.	Quantitative survey involving questionnaires where participants ranked 28 elements of end of life care in order	Of the 28 elements, confidence in the healthcare providers was ranked first while allowance to be included in decision making was one of the least	In regards to home deaths as well care provided is one of the most important factors to be considered by the community nurses that provide support for the quality of home hospice and palliative care. The healthcare providers

giannis and Lam - 2006			of importance to them. Participants were dying patients and their family members.	important elements.	need to be available to the satisfaction of the ill patients as well as that of the family members that are involved in the care at home
Munday, Petrova and Dale - 2009	British Medical Journal (BMJ)	Exploring experiences and perceptions of the general practitioners and community nurses in discussing preferences for discussing place of death with terminally ill patients	Qualitative study using semi structured interviews and thematic analysis. Participants were general practitioners and community nurses.	In the analysis four themes were developed. The professionals experience shed a light to the preference of location for dying patients, the limitations of such preferences that lead often to the choices they make. Professionals with close relationships with the patients can affect the choice of location	The complex nature of location of death requires that medical professions talk about it expressly with their patients. Once a choice is made it is the duty of the nurse to ensure that all that can be done is done to enhance the preferred location of death. Home deaths are limited by the availability of care which leads the patients to choose another location to reduce the burden to their relatives.

Neergaard, Olsen, Jensen & Sondergaard-2008	Biomed Central (BMC palliative care )	To analyse experiences and preferences of bereaved relatives of terminally ill cancer patients in primary care setting exploring barrier and facilitators of good palliative home care	Participants: close relatives of recently deceased cancer patients (patients died less than a year to the time of interviews )Method: 3 qualitative semi structured group interviews of 14 relatives over 5 months	Healthcare professionals needed to improve their management of care to the dying patients. There needs to be shared care between the relatives and the professional when it comes to care and finally the role of the relative in the care needs to be well defined and maintained	Care of a dying patient at home falls upon the relatives as well as the healthcare practitioners and the roles of each need to be well fulfilled for proper care to avoid straining out the relatives leaving them feeling inadequate for not fulfilling the dying wishes of their relatives
Savory, Marco-2009	Biomed central	To describe end of life issues in the acute and critically ill patients	A researched paper describing issues surrounding end of life care for the critically and acutely ill patients	Tackles the following areas: ethical issues, physicians and nurses roles, hospice and palliative care, pain control, Dyspnoea, depression, dementia, cultural and spiri-	The information is necessary in planning end of life care at home to ensure quality of death and efficiency of services provided. The diagnosis of end of life as it approaches is easily done by observation of these issues.

				tual issues, advanced care planning , communication, informed consent, decision making capacity, euthanasia and physician assisted suicide.	
Van der Heide, De Vogel - Voogt, Visser, Van der Rijt & Van der Maus - 2007	Support Care Cancer	To find out if there exists major differences between dying at home or in an institution	Physicians filled out questionnaires while bereaved family members were interviewed. Physicians and bereaved relatives were the participants	The quality of care was judged to be the same in both cases however not all patients that wanted to die at home got to have their wishes fulfilled.	Patients that choose to die at home can be catered just as well as those that chose to die in an institution. There need not be a change in the location of death owing to the lack of care possibilities in the home
Wallerstedt and Andershed - 2007	Scandinavian Journal of Caring Science.	Describe the experiences of nurses in caring for the gravely ill and the dying patients outside special palliative	Qualitative interviews of 9 nurses were tape recorded and analysed according to phenomenological methodology	Ambition , dedication every day activities, responsibility, cooperation, experience, knowledge, feeling and time satisfaction or dissatisfaction were responsible for the kind of experience they	The information gives the involvement and perspective of the nurses while caring for the dying patient in settings of palliative care outside the hospice care institutions.

		care settings		had while caring for the dying pa- tients	
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