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UDC: 616-039.75:64.044.5**

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Master's Thesis

**PROVIDING END OF LIFE COMFORT CARE IN THE NURSING HOME:
EXPERIENCES OF HEALTH PROVIDERS**

Master of Science in Nursing

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Ternopil – 2022

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ABSTRACT

Research shows that nurses and nursing assistants are not sufficiently ready to give adequate comfort care to patients who are at the end of life. The need to further improve quality of care delivery to patients with limited prognosis has been a focal point of various initiatives on different levels such as legislative, clinical and research. The goal of this study was to depict the encounters of health care workers giving solace to patients in the nursing home who are toward the finish of life. This study zeroed in on nurses and nurses' aides in cooperation with one local nursing home in Massachusetts. To achieve this purpose a descriptive qualitative design was utilized. This paper approached the identified phenomenon by interpreting narratives and answers of the participants. A focused group discussion and individual interviews were held. The findings showed that this problem has multifaceted appearances. Few affecting factors were named as main factors that contribute to this delicate and complicated dilemma of delivering comfort care for patients dying in the nursing home. They are insufficient amount of support that facility provides to the health care workers, inadequate patient-nurse and patient –nursing assistant ratio, not receiving enough of end of life care education, patients and their caregivers being in denial of poor and limited prognosis, as well as diminished doctors' involvement. Naturally this study upholds much needed health care workers education regarding how best to provide comfort care at the end of life in the nursing home. Finally, it talks about

the significance of the presented problem to the health care providers and their practices, accompanied by recommendations for further research.

INTRODUCTION

Contemporary health care system and patient care are significantly affected by scientific breaks-through and technological achievements. According to Centers for Disease Control and Prevention (2013), life expectancy has mounted to a 30-year fold increase comparing to the previous century. This is contributed to numerous medical discoveries that led to development of various public health strategies to help people not just extend their lives but live them comfortably to the fullest of their abilities thus having high quality of life and die in a dignified manner. These medical trends also lead to the fact that general public has higher expectations about care delivery especially when it comes to the end of life care.

Relieving suffering while respecting the dying person's wishes has become one of the main goals in the conversation about dying and end of life care according to the National Institute on Aging (NIA) (2021).

The need to improve quality of care delivery to patients with limited prognosis has been a focal point of various initiatives on different levels such as legislative, clinical and research (End-of-Life Nursing Education Consortium (ELNEC), 2008; National Institute of Nursing Research (NINR), 2022). For instance, the ELNEC project is a national education initiative to improve EOL care. Purpose of preparing nursing educators has become its driving force through the implementation of evidence-based content studied in the educational programs of nursing schools into real life everyday practice. As for

research, the NINR has distinguished EOL research as one of its five fundamental examination needs.

Practice shows that within the settings of the nursing homes transfer from one level of care to another (routine to comfort) for a patient with unfavorable prognosis is not a straight forward process. This transition gets affected by various factors. On the caregivers' side, they may not be aware of the signs and symptoms that EOL is accompanied. They may feel indecisive to act on such a major decision. Often complicated family dynamics can result in poor communication between the main decision makers in a family as well.

Hospice or palliative care have become two terms that are frequently utilized reciprocally when it comes to end of life care. Per Ersek et al. (2005), multiple studies endorse the fact that health care workers (doctors, nurses, nursing assistants) lack in their preparedness to provide high quality comfort care. Furthermore, research reflects that inadequate pain control and presence of other unwanted bothersome symptoms at the end of life care are evident and not always taken into significant consideration.

In order to improve care in this patient population reasons and mechanisms behind these care gaps need to be studied, analyzed and worked on. The viewpoint and experience of the individuals working in the nursing home setting who are on the front lines of providing this kind of care has not been fully depicted. Formulating this perspective will help to prevent similar dilemmas from occurring beforehand, thus having positive influence on patients and their families, decreasing moral distress and increasing job

satisfaction of health care professionals, thereby positively impacting health care system and the public overall.

PROBLEM AND SIGNIFICANCE

When it comes to long-term care and end of life care nursing homes most often become stages in the theater of modern health care system. In the context of this paper end of life care is defined as a type of care being provided when a patient has entered irreversible and on-going decline in the health status.

Following the natural life progression and social limitations, aging population whose numbers are rapidly increasing in the USA due to baby boomers generation are more likely to receive care including end of life care in nursing homes. Ersek et al. (2005) claims that approximately 40% of deaths by the year of 2040 will take place in nursing homes. 25% per year is an estimated mortality rate for nursing home residents. Majority of these patients (around 66%) in their final days have remained in their home settings which nursing homes have become for them rather than being admitted to acute-care hospital settings according to their wishes (Keegan et al., 2011). This evidence that most deaths take place within nursing home walls make it almost ironic the fact that many health care workers feel inadequately prepared for delivering high standards of end of life comfort care (Ersek, et al., 2005).

It is known that provision of routine care in nursing homes have been regulated by universal standards established by federal and state entities. However when the light is shed on the provision of end of life care in nursing homes, it reveals not so regulated process that leads to variations (Waldrop & Kirkendall, 2009). Previously mentioned point

about reciprocal utilization of such terms as hospice, end-of-life care, comfort measures and palliative care have contributed to the ambiguity of what end of care in nursing facilities look like (Waldrop & Kirkendall, 2009).

Ersek et al. (2005) point out to various challenges of delivering care in long-term care facilities. For example, they discuss inadequacy and limitation of doctors' communication between them and other nursing home health workers including nursing assistants. They represent approximately 60% to 70% of nursing home employees and subsequently deliver overwhelming majority of direct care which in numbers translates to 70% to 90% (Ersek et al., 2005). Average nursing assistant has a high school level of education or at times even less. When it comes to nurses, research illustrates the trend of licensed practical nurses (LPNs) being more employed than registered nurses (RNs) (Ersek et al., 2005). Amount of end of life care education that LPN programs can fit in their 12-25 months curriculum is rather limited. It explains the burning educational needs of nursing health care workers comparing to other health care arenas (Ersek et al., 2005).

The needed and desired improvement in quality of delivered health care for long-term care patients who are at the end of their life journeys can be achieved through the closer look of the current care standards. This can be a good starting point in understanding what challenges and obstacles health care workers face in their perception of their professional roles. This information will open a curtain to a deeper and more thorough exploration of what health care think themselves regarding ways to improve direct end of life comfort care. One of the steps is to collect and represent health care workers experiences during this research project as this may have the considerable impact

on the well-being of patients and their families as well as the work performance of health professionals, thereby affecting the entire health care system and the public.

LITERATURE REVIEW

Because the end-of-life issues surround every single terminal illness, these delicate ethical problems have become quite prevalent in the health care environment nowadays. The end-of-life issues, which regularly disturb health care providers as well as patients and their families, are apparently associated with the use of biomedical model throughout the United States. This model strongly believes that contemporary medicine and modern technology simply have no limitations. While paying a lot of attention to the scientific method, diagnostics, and disease pathophysiology, biomedical model vigorously attempts to conquer and dominate nature and to overcome death regardless of patients' age and health status. It utilizes the currently available medical, pharmacological, and technological interventions in order to correct congenital and acquired defects, decrease the occurrence of numerous diseases, halt the progression of these illnesses, and delay the resultant death – the previously unavoidable part of the life cycle. Moreover, instead of supporting patients during the natural dying process, this model uses cardiopulmonary resuscitation, mechanical ventilation, dialysis, and artificial nutrition and hydration for bringing patients back to life and subsequently keeping them alive by maintaining their bodily functions. As a result, biological model greatly contributes to the complex dilemmas of direct health care delivery (Birch & Draper, 2008; Meeker & Jezewski, 2008; Waldrop, 2008).

A number of researchers studied health care workers attitude regarding delivering end of life care in the setting of long-term care (Bern-Klug et al., 2004; Denham et al., 2006; Goodridge et al., 2005; Tyree et al., 2005). In 2004 Bern-Klug et al. have conducted an exploratory qualitative study that involved 12 nursing home doctors in order to gain better understanding of physicians perspectives on death and dying as they represent a significant caregivers group. They were interviewed about their views on end of life medical care. Analysis of these conversations has led to the identification of the following aspects. Physicians reported high familiarity with death and dying process. They pointed out that having agreement of parties involved is one of the key elements in delivering good end of life care and having obstacles may disrupt this process. Lastly, nursing home physicians give high importance to the discussion of advance directives with patients and their families as this is a way for them to express and document their wishes regarding end of life care that often dictate them which direction to follow. It would be interesting and useful to have further research investigation regarding how other health care members such as nurses and nursing assistance view importance of the agreement and value advance care directives. Also Bern-Klug, et al. (2004) make an important suggestion to provide more training to the nursing home doctors regarding curative versus palliative care approach at the end of life.

Tyree et al. (2005) have conducted a similar research involving a sample of 607 of nurse practitioners who at the time were attending a national conference. Purpose of this study was to explore end of life care views, perspectives and practices of this health care providers group and their training needs if there were any. Importantly, 30 of these nurse

practitioners were working in long-term care facilities. Participants were asked 20 questions. Analysis of the answers revealed that this group of health care providers felt more comfortable while approaching discussions of end of life care due to their education and experience. Nevertheless, this layer of health care providers felt that they would benefit from being provided with even more education on the subject of interest (Tyree, et al., 2005).

There is smaller amount of research data available on views of nursing assistants as a health care providers group on delivery of end of life care in the nursing home settings (Denham et al., 2006). This group of researchers held nursing assistants as their focus group. The study took place in 6 rural counties across 5 states. Analysis of these conversations has led to the identification of the following aspects. Nursing assistants felt that more education is needed to improve their care. They advocated for better communication skills. This group of health care providers identified such unique theme as developing and maintaining closer connection between patients and themselves (Denham et al., 2006).

Another studied research conducted by Goodridge et al. (2005) analyses outlook of both nurses (N=14) and nursing assistants (N=8) on one hand and patient' families (N=4) on the other hand. The focused time frame of this study is the last 72 hours of long-term care facility residents. Interviews revealed that caring ways of behaving of health care workers were key to the patients' dying process as well as nursing process (evaluating and controlling symptoms, preventing or managing complications, maintaining quality of life as possible, providing social support for families and guide them through end-of-life

issues). Another theme that surfaced in this research was patients' fear of being alone when dying. The conclusion made by Goodridge et al. (2005) is that exercising caring and involved behavior when providing end of life care as well as adequate symptom burden management are vital to the experiences of nursing home patients.

Another research conducted by Flacker et al. (2001) supports the need for more education to health care workers when goal is to provide high quality end of life care to the patients in nursing homes. A group of 27 health care workers practicing in long term care facility that included doctors, nurses and nursing assistances were interviewed on the subjects of how much care patients received and whether death was comfortable. In this instance care was synonymous to amount of direct patient care, symptom control, and emotional support. Results revealed that nursing assistances perceived amount of pain and emotional support differently. Comparing to doctor and nurses, they felt that patients had more pain and they valued emotional support provided to families more as well. This research recommended health care providers to use individualized care plan as this will create an opportunity for them to better realize the difference in their own end of life views and believes (Flacker et al., 2001).

As a collective summary one may realize that the cited researches endorse the idea of existing lack of knowledge about end of life care provision amongst health care workers as well as their differences in what quality end of life care looks like. In order for a health care team to function effectively and productively to the benefit of their patients these differences need to be explored and worked on as this will lead to higher job satisfaction and better outcomes for the patients and their families.

It is beneficial to look at few studies about what constitutes the challenges and barriers in improving comfort care at the end of life. First research in focus was conducted by Hanson et al. (2002) who examined 77 experienced nursing home workers including doctors. A number of themes were identified as a result. They include inadequate training and staffing ratio, inconsistent staff issues, focus on rehabilitation, and doctors low regards to end of life (Hanson et al., 2002). Concept of good death was discussed in this study as well. Participants believed that a dignified death of a patient in a nursing home was a result of being given consistent caregiving by the same health care team that have excellent teamwork spirit paired up with developing and executing effective individualized multifaceted care plan that focuses on both physical and emotional aspects of caring (Hanson et al., 2002).

Another research that studied barriers through the eyes of health care workers was work conducted by Stillman et al. (2005). This project was a part of a bigger palliative care initiative that involved over 300 nursing homes. The long term care facilities of the focus ran an 18-months comprehensive palliative care program. Researches were interested how this factor would influence perception of the health care team on end of life care, the potential barriers they meet, and level of knowledge. Total of 539 nursing home workers completed the same questionnaire revealing that having palliative care program in the facility increases level of understanding and education about dying and comfort care among health care workers. When discussing barriers, the following factors were named: communication with patients' families, ambiguities about pain management, and administrative worries zeroed in on effective results (Stillman et al., 2005).

To summarize, it is studied via multiple research literature that lack of proper staffing, not having enough of administrative support, insufficient staff training, regulatory issues, and doctors disregard for end of life care issues are named as main challenges in provision of high quality end of life care to nursing home patients. As a number of people finding themselves in long term care setting at the end of life increasing and this number is only anticipated to grow, it is of vital necessity to address these barriers on the road to improvement of death experience for many Americans.

Another part of research surrounding end of life care in nursing homes circles around differing perceptions about care itself amongst health care workers and their knowledge level about this type of care. There was a number of themes identified that differ in end of life care perception. They consist of views on pain level and other bothersome symptoms experienced by patients and ways to manage it, amount of emotional support given to patients and their families by various health disciplines. The later included amount of time spent with the patients and the bond developed between health care workers and patients. Across all studied research health care workers on various levels have shared the need for more education and unfavorable lack of experience in providing end of life care.

METHODS

Exploring health care workers knowledge, experiences, and perceptions in the context of the end of life comfort care of long term care facility patients has been the main goal of this project. A special attention was paid to what participants identified as factors improving or on the contrary challenging their practices. The study was conducted in one

local nursing home in Massachusetts via individual interviews and a focus group discussion.

DESIGN

In order to complete this project a descriptive qualitative design was utilized. This type of an approach is rather flexible and exploratory in its nature (Oman et al., 2003). It can be facilitated when there is not much information about nursing related subject or concept is available.

A convenience sample of health care workers including nurses and nurses assistants who provide care in the settings of a nursing home were chosen to take part in this project. One of the inclusion characteristics of the participants was presence of the experience with providing comfort care to patients with limited prognosis. One of the exclusion characteristics of the participants was inability to clearly communicate in English language. All 15 interviewee were English-speaking females, ages of 21 to 40 years old, currently working as registered nurses, licensed practical nurses, or nurses' aides and had one to five years of EOL care experience. The researcher deemed this sample size to be adequate because of the in-depth nature of the interview that were conducted in an individual fashion and at separate time ensuring privacy to the participants.

As the data was processed and analyzed a number of themes was identified: comfort care definition, delivery of comfort care, facilitators of end of life care, barriers and challenges to end of life care, end of life education and training provision, and improving EOL comfort care.

COMFORT CARE DEFINITION

One of the first topics that participants were discussing was how they define comfort care at the end of life in the nursing home settings. It was noted that certain similarities appeared in these conversations. Here is an example that one of the nurses shared regarding her views on the subject: “In my professional mind comfort care at the end of life is ensuring that my patients don’t suffer from pain or any other symptom such as shortness of breath. I also value comfort of their spirit. I firmly believe that no one should die alone. That’s why I also let my patients know that I am here for them even when they are unresponsive. I have a vivid memory of one of my dying patients I took care of when I was a nursing assistant who had no family. I felt compelled to come and sit with him even after my shift was finished as this way I knew he was at peace and not alone at this critical time of his life”. It was more than one person who shared having similar experience when they would donate their own time in order for dying patients not be alone. All discussions about care were circulating around care and support of the dying patients.

Recurrent answer was “make and keep patients free of pain”. Another simple and generalized reply by health care workers was that it is their essential responsibility “to ensure patients’ comfort at all times including end of life”. Few participant pointed out the importance of not just physical body but also emotional and at times spiritual body commenting that “our souls are dying along with our bodies”. Few nursing assistant draw attention to specific aspects of physical care as “mouth care and incontinence care as well as repositioning”.

To summarize the responses it should be noted that overall responses were similar in ways how health care workers in nursing homes define comfort care at the end of life.

Table 1

Definitions of Comfort Care

Nursing Assistants	Nurses
Patient is made comfortable	Patient is made comfortable
Follow patient wishes	Prevention of bed sores
Loving touches and smiles	Eliminate extreme measures
Providing care that makes patient pain free	Patient is pain free
Ensure room quiet	Patient is never left alone
Positioning for comfort	Give patient full attention
Offer patient a relaxing environment	Make sure patient relaxed
Keeping patient clean	Patient is anxiety free
Doing whatever makes patient happy without causing harm	All aspects of care
Patient is without respiratory distress	Patient is comfortably breathing
Soft strokes to hair	Not taking extreme measures
Involve family with care	Family involvement
Mouth care	Symptom management

DELIVERY OF COMFORT CARE

The second research theme was about ways of delivering comfort care by various health care workers in nursing homes. Despite of one role—nurse or nursing assistant—similarities were noticeable in the discussion of this question. To sum it up comfort care delivery was viewed as ensuring patients' comfort and supporting patients' families and loved ones. Involvement of hospice services in cases of patients at the end of life did not change quality of care clients received according to the answers of the participants. However nursing assistants were commenting that direct patient's care with no hospice took longer time. One of the nurses shared that “regardless of hospice involvement I treat all the patients with respect, care, and dignity”.

When it came to differences, it was noted that they were dictated by person's job title. Thus nurses were primarily oriented with pharmacological and physiological side of the dying process management whereas nursing assistants' focus layer was on custodial part of personal care. To illustrate this point here is an answer of one of the nurse's responses to the discussion of how care at the end of life is being provided: “I need to frequently assess patients to determine if the current plan of care is effective. My focus of care is not only patients themselves but their families as well as their views and perception on dying as they affect the comfort level of my patients. Another nurse pointed out that “delivering care also means following patients' wishes and advocating on their behalf when they are not capable of doing so”.

Nursing assistant were focused on personal care of patients and support of their families. Here is an example of one of the answers: “My job is to do for patients what they cannot do for themselves when it comes to their hygiene. I also want to make them feel

respected when I enter their personal space”. Another nursing assistant included family in her ways of delivery care at the end of life. Here is how she described it: “I care not only about the dying person but about their loved ones too. A simple act of kindness can go a long way. In one case it may mean that I just need to bring an extra chair into the room and in another case to listen to them and let them know that I will take care of their loved one when they go home”. Nourishing not only soul but the body as well when providing care was reflected in another nursing assistant’s reply: “I always offer coffee and water along with some pastry from the kitchen to the families as they spend time at the bedside”.

Analysis of the answers shows that nurses and nursing assistant focus on different aspects of care delivery based on their roles. For nurses it is oriented on pharmacological and physiological aspects of one’s functioning. For nursing assistances it is focused on delivery of personal care to patients and their families. All health care workers did not feel that patients’ care delivery was any different with hospice layer being added to a case or not.

FACILITATORS OF END OF LIFE CARE

The third topic was focused on the facilitators of comfort care to the nursing home patients with poor prognosis. Main element of these discussions was evolved around being a team as opposed to a separate individual when delivering comfort care to dying patients. All participants felt that practicing team approach was effective. Nursing assistants commented that they found helpful when nurses help them to identify patients entering the active stages of dying. Nurses in their turn point out common signs of death being rather

imminent (irregular respiratory pattern, death rattle, cyanosis of bilateral upper and lower extremities).

Another point of discussion was use of the complimentary therapies to aid with the provision of comfort care in the final days of patients' lives. This interventions include utilization of aroma therapy playing calm music, and providing books to families, so they can read to the patients. One of the nurses reflected on such practices sharing that "these small things meant a lot to families and patients and they really were excellent addition to what we, care workers, could do. It made them calmer and more peaceful, so they could relax more and deeper".

Staffing issue was identified as a factor that had negative influence on care quality. However participants explained that practicing team approach has allowed them to balance this issue and as a result quality of care was not significantly affected. So one of the nurses shared: "There are times when we have inadequate staffing but we do our best to work as a team and it always works out". Nursing assistants echoed these opinions reflecting the following: "We do our patient care rounds together and this way it is easier for us and patients. By providing care this way we may have more time to actually sit down with patients and either talk to them or hold their hand".

Analysis of the answers on this part of the study shows that teamwork and use of certain complimentary therapies at the end of life care are perceived by health care workers as facilitators of comfort care.

BARRIERS AND CHALLENGES TO END OF LIFE CARE

For the fourth point of this study barriers and challenges while providing care to the dying patients in the nursing home settings were examined. A number of concerns were pointed out by the participants.

Both nurses and nursing assistants felt that they did not have enough time to provide high quality care at the end of life. They shared that their caseloads were not adjusted in relevance to the acuity of patients on their assignments. This was perceived as a barrier as well. Upon further discussions, participants explained that they felt not having enough administrative support in matters of staffing. One of the nurses shared that “I feel that there are times when I simply cannot provide desired amount of care and attention to patients and their families as I am overwhelmed with other patients’ needs that I am obligated to meet as well. This can be very frustrating and leads to feeling like a failure at times. What makes matters even worse is that I think that administration does not really care how we feel and why or at least not always”.

Another obstacle that was named by participants was patient and families lack of acceptance of the limited prognosis often times stemming from the fact that doctors don’t properly and openly discuss this part of patients’ health care paradigm. Here is an example of what one of the nurses shared when making this point: “One of the most challenging cases I had in my practice was a patient who was in denial regarding his heart disease progressing towards the end stages. This belief was supported by his physician who continued to focus on the curative side of his disease at the time when patient was failing and desperately needed comfort measures. He was given false hopes and this played major negative role in his final days”.

Both nurses and nursing assistant felt that they did not receive enough training and education prior to their work. Few nursing assistants shared that they never had any kind of formal training how to provide end of life care until they actually started to work and their more experienced colleagues trained them. One of the participants with three years of experience in the field expressed sadness when she was sharing that “I could have made more patients comfortable should I knew back then what I know now”.

When questioned about the knowledge of health care workers on the nursing home policies and procedure of end of life care provision, they appear not to be aware or familiar with such. Participants were not sure if this would be helpful or rather create another obstacle in delivering comfort care to the dying patients. One nurse shared “I am not aware of these policies in my work place and I actually have high degree of doubt if it would help. We need practice and advice, not just dry rules and tight regulations”.

Participants consensually identified a number of interconnected barriers leading to decreased quality of care at the end of life in the setting of long term care facility. They are not having adequate time and lack of staffing, not being supported by the administration, not having desired level of end of life care education and training, patient and family poorly accepting limited prognosis, lack of honesty in ways physicians communicate with patients and families, not being familiar with facility end of life care policies.

END OF LIFE TRAINING AND EDUCATION

All of the participants raised a point of not being provided with structured and targeted end of life care formal education during their school years. Majority of them indicated that their experience and knowledge of end of life care was from actually

working on the site with more experienced nurses and nursing assistants. This particular nursing home offers a one-hour annual in-service about end of life care but participants felt that this was not enough of education and training for such complex matter. Few nursing assistants openly shared that “I was never formally educated on this subject. All my training is based on the care instructions from an experienced nurse I worked at the dawn of my career”. Another nurse stated “I feel that my education was not adequate on this subject and so I was scared of the dying before I started to work with elderly population. Now they all have human faces attached to their names. It’s no longer a textbook but real life. I wish I had more real life training before I had to provide this kind of care to real people”. One of the participants brought a unique point when she said “I wish I had more knowledge about this and done more thinking while reflecting on my own mortality, so I would be better prepared emotionally to take this kind of load onto my heart and soul”.

All of the participants agreed that it would be highly beneficial to them and their patients if they were given more knowledge and training about death and how to provide care at the end of life.

IMPROVING END OF LIFE CARE

After studying the drawbacks surrounding end of life care, participants were invited to discuss ways of improving comfort care provision by health workers involved in the process. Based on the previous discussions, it is not surprising that all of the participants agreed that being given more education and training about death and comfort care would benefit patients as recipients of care and health care workers as care givers.

Mostly nurses felt that they could provide better quality of care to the dying patients in long term care settings if the administration was more considerate of the acuity of such patients when assigning case load to the nurse. Few participants also advocated for continuity and consistency of providing care to the dying explaining that “you get to know your patients and what comforts them and what makes them unhappy. Besides they get sick and tired of telling their story each time new face appears in the picture”.

Mostly nursing assistants and few nurses indicated the need to have some kind of bereavement support for them as they develop a special kind of connection with the patients while providing comfort care to nursing home patients who are at the end of life. Here is the most emotionally charged answer of a participant who shared that “taking care of the dying is very difficult for me and many of my colleagues. By being the witnesses of the dying process we are forced to think about our own death. It’s not the easiest task. Besides the connection that we build and cherish is not going anywhere. We miss our patients, we love them, we care but because we are not their family we are not thought to be hurt as much. We are vulnerable as well because we are humans too even though at this time we are on the other side of the fence but one day we will be patients ourselves”.

DISCUSSION OF RESULTS

A qualitative, descriptive study was completed using data from individual interviews and a focus group discussion. The goal of this project was to gain better understanding of the perspectives on end of life care delivery of health care workers in the settings of long term care facility.

The discoveries of this study supported that the variables affecting comfort care of patients with limited prognosis are multi-layered, and would benefit from various interventions aimed at increasing quality of end of life care. Information was collected and analyzed detecting certain themes that will be compared with literature about end of life care. Limitations of this study will be acknowledged. Finally, obtained information will be braided into current health care practice with recommendations for future research being pointed out.

It was noted that definition of what comfort care constitutes was described in a similar way by the participants whereas the differences in such descriptions stemmed from their professional roles. Nurses tend to focus on pharmacological and physiological side of the dying process management whereas nursing assistants' focus layer was on custodial part of personal care.

Study conducted by Goodridge et al. (2005) came to similar conclusions about various health care workers having different views about comfort care based on their roles. The overall agreement on essential elements of comfort care being pain free death with dignity echoes the findings of this study.

Teamwork and use of certain complimentary therapies at the end of life care are perceived by health care workers as facilitators of comfort care within the limits of this study. However nurses felt that due to constraint of time available they cannot spend as much time with their patients as they would like to. Similarly findings of Forbes-Thompson and Gessert (2005) study reveal that support of each other in a health care team

translates into positive outcome and measured by higher job satisfaction and quality of delivered care to patients with limited prognosis.

A number of interconnected barriers leading to decreased quality of care at the end of life in the setting of long term care facility were identified. They are not having adequate time and lack of staffing, not being supported by the administration, not having desired level of end of life care education and training, patient and family poorly accepting limited prognosis, lack of honesty in ways physicians communicate with patients and families, not being familiar with facility end of life care policies. Participants in the Goodridge et al. (2005) study found themselves dealing with similar barriers while providing comfort care to dying patients. They shared that taking care of less patients with higher care needs would be beneficial to patients and their families.

Participant of this study also identified that not having enough administrative support in matters of staffing was negatively effecting comfort care. Additionally they strongly advocated for patients having consistent health care workers as this ensures continuity of care resulting in higher quality of end of life care. Study of Hanson et al. (2002) supports these outcomes pointing out insufficient stuffing as an essential challenge in improving quality of end of life care.

All of the participants multiple times have identified lack of structured and targeted end of life care formal education during their school years as another barrier to providing quality end of life care. Multiple studies have echoed these educational deficiencies. For example, study conducted by Ersek et al. (2005) have similarly encountered insufficient training and education of nursing home health care workers who provide end of life care.

Other worldwide studies have proven the idea that when education in the facilities is being provided to the health care workers their knowledge and confidence grow accordingly (Braun & Zir, 2005; Easom et al., 2006; Keay et al., 2003; Paice et al., 2008).

Another obstacle that was named by participants was patient and families lack of acceptance of the limited prognosis often times stemming from the fact that doctors don't properly and openly discuss this part of patients' health care paradigm. Research conducted by Forbes-Thompson and Gessert (2005) endorses the fact that ineffective and not straightforward communication between patients, their families and doctors becomes another barrier in providing higher quality of comfort care. Furthermore, work of Ersek et al. (2005) shows that physicians are hesitant to have open discussion about poor prognosis with patients and their families.

Participants welcomed the opportunity to discuss ways of improving comfort care provision by health workers involved in the process. Receiving more education and training about death and end of life care was mentioned by majority of participants on numerous occasions. Having more of administrative support to the health care workers was suggested. In particular providing some kind of grief counselling to staff was suggested by few participants. These observations are supported by other researchers as well (Denham et al., 2006; Flacker et al., 2001; Hanson et al., 2002). These works discuss that health care workers providing end of life care in nursing homes would greatly benefit from having counselling support ensuring emotional readiness for patients' deaths and how to address the emotional attachment they develop towards patients and their families while providing care.

LIMITATIONS

There are few limitations to the conducted study. Firstly it was completed in one local nursing home which does not allow make any generalizations about the outcomes. Second limitation is related to having only perspective of nurses and nursing assistants as physicians and nurse practitioners did not participate in the study conversations. Their input expressed via direct interviews would have enriched this study as they provide care at the end of life from a different perspective. Another layer that would enhance the results are experiences of patients and their families themselves. Lastly, not all the responses that were received were clear to interpret and seem off-topic in spite of authors' attempts to be considerate of needed literacy level.

CONCLUSION

Experiences and perspectives of nursing home care workers in particular nurses and nursing assistants while providing direct comfort care to the dying patients were studied in this research. Individual interviews and focus group were conducted to gather information that was later analyzed and certain themes were detected. In particular discussions about what constitutes comfort care, how it is delivered, and what barriers and facilitators health care workers face while delivering comfort care. An undeniable lack of education and practical training regarding end of life care was identified across all disciplines involved in the research. It was concluded that definition of comfort care has more similarities than differences in the eyes of the participants. Later were dictated by one's professional role: nurses were focused on physiological and pharmacological part of the dying process whereas nursing assistants were concentrated on the provision of direct patients' care and

live interactions. Goodridge et al. (2005) study revealed similar findings when discussing provision of comfort care to dying patients in nursing homes. Team work was identified as a strength and facilitator. As for barriers, lack of education, practicing open communication between patients, their families and physicians, inadequate staff-patient ratio often leading to inconsistent staffing, lack of grieve counselling support services available to health care workers themselves, and lack of acknowledgement and familiarity with facility's policies and procedures regarding provision of comfort care were identified. These barriers to delivering high quality end of life care to patients in long term care facilities were identified and discussed in other researches (Denham et al., 2006; Flacker et al., 2001; Hanson et al., 2002). (Denham et al., 2006; Flacker et al., 2001; Hanson et al., 2002).

Participants offered their perspective on ways of improving comfort care provision. Receiving more education and training about death and end of life care was identified by majority of participants on numerous occasions. Having more of administrative support to the health care workers was also suggested. In particular providing grief counselling to staff was suggested by few participants.

Results of this study echo experiences and perceptions of other health care workers in different long term care facilities pointing out to few challenges and need for change in order for patients to receive high quality end of life care. Dying comfortably with peace and dignity is an undeniable right of every human being.

IMPLICATION FOR PRACTICE

This study can benefit health care workers in various ways. It is suggested that development and implication of mandatory end of life education courses and hands-on training sessions were made available to health care works in nursing homes. Inclusion of physicians and administrative staff in these programs is highly recommended in hopes that improved communication and awareness of the health care workers challenges would result.

Another implications for health care workers is a strong recommendation to develop and maintain supportive grieving counselling available to those who provide care to patients at the end of life.

On a larger scale of things increased attention to the funding of proving end of life education is needed along with attention to more adequate staffing ratios in the setting of long term care facilities. This would lead to a higher satisfaction of the health care workers and subsequently higher quality of end of life care.

RECOMMENDATIONS FOR FUTURE RESEARCH

Considering the above discussed limitations it would be recommended to conduct research that would include a larger number of nursing homes. Additionally inclusion of perspectives and experiences of other participants (physicians) and receivers of the care (patients and their families) would help to enrich and broaden the results.

REFERENCES

- Bern-Klug, M., Gessert, C. E., Crenner, C. W., Buenaver, M., & Skirchak, D. (2004). 'Getting Everyone on the Same Page': Nursing Home Physicians' Perspectives on End-of-Life Care. *Journal of Palliative Medicine*, 7(4), 533-544.
- Birch, D., & Draper, J. (2008). A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *Journal of Clinical Nursing*, 17, 1144-1163.
- Braun, K. L., & Zir, A. (2005). Using an interactive approach to teach nursing home workers about end-of-life care. *Journal of Hospice & Palliative Nursing*, 7(5), 280-288.
- Centers for Disease Control and Prevention (2013). *The State of Aging and Health in America 2013*. Retrieved from <https://www.cdc.gov/aging/pdf/State-Aging-Health-in-America-2013.pdf>
- Denham, S. A., Meyer, M. G., Rathbun, A., Toborg, M. A., & Thornton, L. (2006). Knowledge of Rural Nurses' Aides About End-of-Life Care. *Family & Community Health*, 29(3), 229-241.

- Easom, L. R., Galatas, S., & Warda, M. (2006). End-of-life care: and educational intervention for rural nurses in southeastern USA. *International Journal of Palliative Nursing*, 12(11), 526-534.
- End-of-Life Nursing Education Consortium (ELNEC). (2008). Retrieved from http://sdhospice.learn.com/files/pdf/ELNEC_FactSheet.pdf
- Ersek, M., Grant, M. M., & Kraybill, B. M. (2005). Enhancing End-of-Life Care in Nursing Homes: Palliative Care Educational Resource Team (PERT) Program. *Journal of Palliative Medicine*, 8(3), 556-566.
- Flacker, J. M., Won, A., Kiely, D. K., & Iloputaife, I. (2001). Differing perceptions of end-of-life care in long-term care. *Journal of Palliative Medicine*, 4(1), 9-13.
- Forbes-Thompson, S., & Gessert, C. E. (2005). End of Life in Nursing Homes: Connections Between Structure, Process, and Outcomes. *Journal of Palliative Medicine*, 8(3), 545-555.
- Goodridge, D., Bond, J. B., Jr., Cameron, C., & McKean, E. (2005). End-of-life care in a nursing home: a study of family, nurse and healthcare aide perspectives. *International Journal of Palliative Nursing*, 11(5), 226-232.
- Hanson, L. C., Henderson, M., & Menon, M. (2002). As individual as death itself: a focus group study of terminal care in nursing homes. *Journal of Palliative Medicine*, 5(1), 117-125.
- Keay, T. J., Alexander, C., McNally, K., Crusse, E., & Eger, R. E. (2003). Nursing home physician educational intervention improves end-of-life outcomes. *Journal of Palliative Medicine*, 6(2), 205-213.

- Keegan, L., Drick, C. A., & Watson Caring Science Institute. (2011). *End of life: nursing solutions for death with dignity*. Springer.
- Meeker, M. A., & Jezewski, M. A. (2008). Metasynthesis: Withdrawing life-sustaining treatments: The experience of family decision-makers. *Journal of Clinical Nursing, 18*, 163-173.
- National Institute on Aging (NIA). (2021). *Providing Care and Comfort at the End of Life*. Retrieved from <https://www.nia.nih.gov/health/providing-comfort-end-life>
- National Institute on Health. (2004). *Statement on Improving End of Life Care*. Retrieved from <http://clk.about.com/?zi=1/XJ&sdn=dying&zu=http%3A%2F%2Fconsensus.nih.gov%2F2004%2F2004EndOfLifeCareSOS024html.htm>
- National Institute of Nursing Research (NINR). (2022). Retrieved from <http://www.ninr.nih.gov/>
- Oman, K., Kregman, M. E., & Fink, R. M. (2003). *Nursing research secrets*. Philadelphia: Hanley & Belfus.
- Paice, J. A., Ferrell, B. R., Coyle, N., Coyne, P., & Callaway, M. (2008). Global efforts to improve palliative care: the International End-of-Life Nursing Education Consortium Training Programme. *Journal of Advanced Nursing, 61*(2), 173-180.
- Stillman, D., Strumpf, N., Capezuti, E., & Tuch, H. (2005). Staff Perceptions Concerning Barriers and Facilitators to End-of-Life Care in the Nursing Home. *Geriatric Nursing, 26*(4), 259-264.
- Tyree, T. L., Long, C. O., & Greenberg, E. A. (2005). Nurse practitioners and end-of-life care: beliefs, practices, and perceptions. *Journal of Hospice & Palliative Nursing, 7*(1), 45-51.

- Waldrop, D. P. (2008). Treatment at the end of life. *Journal of Gerontological Social Work*, 50(1), 267-292.
- Waldrop, D. P., & Kirkendall, A. M. (2009). Comfort measures: a qualitative study of nursing home-based end-of-life care. *Journal of Palliative Medicine*, 12(8), 719-724.