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End of Life Quality Measures

by

Sheila Marie Oliver, B.S.W., B.A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work

St. Catherine University and the University of St. Thomas
St. Paul, Minnesota

In Partial fulfillment of the Requirements for the Degree of

Master of Social Work

Committee Members

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis or dissertation.

Abstract

This paper explores end-of life quality measures and their relationship to medical versus non-medical hospice and palliative staff. More specifically, “There is a difference between hospice and palliative care medical versus non-medical staff views in relation to end-of-life quality measures.” This study included 121 hospice and palliative care medical and non-medical staff. The staff was from one hospice program in a metropolitan area. The participants were contacted through an anonymous, on line survey package called Qualtrics. The survey did not find any statistical significance to the research question but did find some interesting implications about views of end-of-life quality measures. One conclusion is that medical and non-medical hospice and palliative care staff seems to view the quality measures very similarly and value these measures with high regard. Further research is needed, however, to help solidify the value of quality measures and the involvement of the patient and family in end of life care. More research in end-of-life quality measures would also assist in proving that there is a greater need for these services and that an increase could actually help save health care dollars.

Keywords: End-of-Life Quality Measures, Hospice and Palliative Care

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Hospice and palliative care are growing end-of-life services across the United States. Palliative care is often used interchangeably with hospice care even though there are fundamental differences between the two in service and funding. Key to both services, however, is symptom control and patient and family centered medical care. As these programs have developed over the past thirty years an immense amount of time and energy has been put into assessing the satisfaction of the patient and family members involved in these services. This is evidenced by the research done on satisfaction and reliable indicators, for example, patient and family satisfaction surveys sent out by hospice programs. End-of-life quality measures are used to develop these satisfaction surveys. End-of-life quality measures are those elements of care that are important to the patient and family. Having one consistent visiting nurse or dying at home versus a nursing home are examples of quality measures. Researchers have taken these elements and developed several different tools to gauge satisfaction. While developing those measures from the perspective of the client is important, it would be of equal significance to understand how the professionals delivering the care view those measures. Current research explores the impact of quality measures on patient satisfaction. This researcher found one study that explored how the professionals working in hospice and palliative care value these measures. No studies have examined how the medical versus non-medical professionals of hospice and palliative care differ in perspective of these measures.

According to the National Hospice and Palliative Care Organization's (NHPCO) 2011 report, hospice served only 25,000 people in 1982 as compared to 1,650,000 in 2011. With the increasing number of individuals using hospice and/or

palliative care comes an increasing number of corresponding research studies that include, but are not limited to, program efficiency, satisfaction with the service, timing of hospice and palliative referrals and quality of life measures. Central to all of the research reviewed are indicators that measure quality at end of life.

Examples of these indicators are; accurate and consistent information, stop treatment when it no longer is helpful, responsive to emotional needs, treat the whole person not just the disease, acknowledge and respect personal beliefs, give enough information so an understanding of the illness and treatment is present and take into account personal wishes when treating symptoms (Engelberg, et al, 2010). An analysis of the following literature will reveal that research done around end of life quality measures is in the form of satisfaction surveys administered to families after their loved one has died. No research was found on how medical versus non-medical professionals view end-of-life quality measures.

Literature Review

Research reveals a lack investigation into end of life quality measures from the viewpoint of the professional staff, both medical (MD, RN, NP or Home Health Aides) and non-medical (Social Workers, Chaplains, Administration and Office Staff). A few reasons come to mind when discussing the lack of research in this particular area. The U.S. is a country focused on the satisfaction of the customer, which is important. That also explains the overabundance of studies on patient and family satisfaction and patient and family views on end of life quality measures. Another significant reason is that it is assumed that “everyone” holds the same quality measures as important, for example, an oncologist may assume that the most

important thing is symptom management for nausea, pain or anxiety where the social worker may feel that meeting emotional needs is most important. Measures of quality are being established across the country in all forms for health care but no research indicates the comparison between medical and non-medical staff in regard to end of life quality measures and the value each professional places upon them.

Hospice Quality Measures and Satisfaction

Research done on hospice end of life quality measures and satisfaction focuses on the family member or caregiver of the patient and many surveys are sent after the patient has died. One such study done by Connor, Teno, Spence and Smith, (2005) was a voluntary survey on a website by family members on behalf of the decedent. This survey was one of the validation tools that the NHPCO (National Hospice and Palliative Care Organization) used to develop their current family satisfaction survey. Via a website family members were encouraged to answer a 61 item questionnaire that surveyed them about the care provided to the decedent by the hospice program. This same survey was used in a 2008 study done by Rhodes, Mitchell, Miller, Conner and Teno. The research focused on the results of one year of the Family Evaluation of Hospice Care, Connor, et al, 2005 using the data from the first two quarters of 2004 and 29,292 surveys and Rhodes, et al, 2008 using the data from the entire year of 2005 and 116,974 surveys. Given the size of the research data used and the validity of the survey tool it could be surmised the accuracy of the research done. Both studies indicated that this questionnaire is based on a conceptual framework of patient-focused, family centered medical care. It acknowledges the importance of involving family in the care of the patient. The

researchers found that programs that scored high on satisfaction surveys were the programs that provided physical comfort and emotional support, encourages shared decision making, is respectful of the patient, provides the family with appropriate information and emotional support and coordinates care effectively. All of these being significant end of life quality measures. Another study done by McLaughlin, Sullivan and Hasson in 2007 supports the findings of Connor, et al., (2005) and Rhodes et al., (2008). A total of 128 people responded to a postal questionnaire. Even though this study had only eight questions and was initially piloted on other professionals and not families it does seem to support other studies with larger amounts of respondents with more encompassing questions. This study suggests that the programs that fail to coordinate care, have communication breakdown between the professional disciplines, are not confident in hospice services and fail to communicate and educate loved ones on service and the dying process score significantly lower than their counter parts that master these areas. This study also supports the notion that emotional support is just as important to the family as it is to the patient. A final study by Fontaine and Rositani, 2000 studied the impact of hospice nursing visits from nurses who were employees of the hospice versus those who were contracted from the outside. A total of 373 patients and family participated. This study echoes the importance of care coordination, respect, accurate information sharing and emotional support for the patient and family. This study emphasizes the nurse in relation to those factors and how important that nurse is in establishing a mutual understanding of those end of life quality measures as well as overall quality and cost containment efforts.

While the studies above talk specifically to end of life quality measures and how it relates to the patient and family experience of hospice and palliative care they do not explain how medical versus non-medical professionals value the same quality measures.

Other studies that focus on hospice quality measures and satisfaction involve the programs that offer additional social work hours of service and quality after hours support. Three such studies Archer and Boyle, (1999), Reese and Raymer, (2004) and Empeno, Raming, Irwin, Nelesen and Lloyd, (2013) all stress the importance of additional social work involvement in the delivery of care. The study conducted by Empeno, et al, (2013) implies that by increasing the involvement of social services more resources were made available to caregivers in the form of grants, respite hours and other community services that relieved caregiver stress and exhaustion. Programs that have piloted this change saw a reduction of family stress and scored higher in the satisfaction survey in the areas of feeling supported, feeling safer and more secure in the caregiver role. The hospice staff identified participants from the clients on their caseload. They were to identify caregivers that seemed particularly stressed but give no identifiable measure as to what stressed looks like. Validity is questionable due to the professional staff's ability remain objective when choosing participants. The study done by Reese and Raymer, (2004) supports the previous survey's findings and further states that additional social work involvement has shown better interdisciplinary team functioning, more issues that could affect positive outcomes being addressed, a reduction in medical focused services, less visits required by the nurse and increased patient and family

satisfaction. These researchers pose that all of these desired outcomes are possible because social workers advocate for the patient and their involvement in their own care, mediate between the patient and difficult family dynamics, clarify communication breakdown between the patient, the family and the professional staff involved in care. They are also able to locate community resources that can reduce cost and increase quality of the hospice and palliative services. This study was completed with 330 participants from 66 different hospice programs equating with 5 participants per hospice. The data from this study was entered into SPSS, assigning one line of data for each patient. This study is consistent with other research indicating that social workers do have an impact on end of life quality measures for the patients they serve in hospice. The final study by Archer and Boyle, (1999) was the administration of the Primary Caregiver's Satisfaction Survey in relation to their satisfaction with the services provided by the social work staff. The survey was administered via phone, which could sway the respondent to give positive answers. Another weakness is the sample size of this study was 55 primary caregivers and the phone survey was conducted at least six months after the death of their loved one. The studies findings were 84 percent of respondents stated they were very please with the social worker's involvement. The family felt the social worker was respectful and open in communication and felt that they helped orchestrate a smooth service delivery by the whole interdisciplinary team. Furthermore, the social worker was felt to have the patient's best interest in mind and was able to successfully support the caregiver during the process. While the

findings are similar to other studies conducted the accuracy is in question due to sample size and the amount of time between survey and death.

All of the studies reviewed were specific to end of life quality measures and how they relate to patient and family satisfaction regardless of the focus of the study. Each study was helpful in establishing what characteristics are important to the patient-family unit for end-of-life care in hospice. By comparing the studies, one can begin to see trends in measures that rank consistently high from research to research which can be helpful in establishing a list of quality measures for this study.

Palliative and End-Of Life Care Quality Measures and Satisfaction

Research studies done on palliative care and end-of-life care are plentiful in regard to the quality measures. The first three studies discussed quality measures and satisfaction as it relates to specific programs. The study done by Ringdal, Jordhoy and Kaasa (2002) from Norway was conducted with a control group and the group admitted to the intervention program. The intervention group had a navigation team that helped them make sense of their treatment options and negotiate the health care system. They also had regular conferences to check in and be able to ask questions. The control group was left on their own to be treated by specialists with no help to navigate. Of the three indicated, this study was the only one that used a control group. Between the two groups, the intervention program group was significantly more satisfied with aspects of the patient's care or quality measures, for example, pain control, information given about the patient's prognosis or availability of the doctor to the patient or family. Similarly, the other two studies,

Hedlund (2013) done in the U.S. and Kennett and Payne (2009) done in London, found that open communication about their illness and the ability to ask questions were two major quality measures when the patients found out that their disease was no longer treatable. Both studies indicated that having control of the direction in which their health care went from that moment on was of utmost importance. Both groups were appreciative of professional staff that delivered the “bad” news in a sensitive manner and did not evade the topic or close the door on discussion.

Techniques to gauge end of life quality measures were the focus of two studies, *Measuring the Quality of End-of-Life Care* by Engelberg, Downey, Wenrich, Carline, Silvestri, Dotolo, Nielsen and Curtis (2010) and *Measuring End-of-Life Care Outcomes Retrospectively* by Teno (2005). Both studies identified quality measures that were meaningful to the subjects in their research. The study done by Engelberg, et al., had a large sample size of 1996 with participants from two different regions of the United States. The study done by Teno reviews existing research that uses the post mortem satisfaction survey design. Both studies essentially listed the same measures, for example, the importance of physical comfort, emotional support, shared decision making, communication, support to patient and family members alike and health care accessibility. These studies indicated that an absence of these measures were indicative of poor quality of care and dissatisfaction. Another aspect that both studies agree on is “researchers have suggested that appropriate measures of the quality of end-of-life care must specify which aspects of quality are being measured, that is, whether an instrument is assessing the quality of life, the quality of care, or the quality of dying and death”

Engelberg et al. (2010, p.952). This is a key element when determining quality measures and to fully understand patient and family perspectives on death and dying. In addition to these studies, other research done by Brumley, Enguidanos, Jamison, Seitz, Morgenstern, Saito, McIlwane, Hillary and Gonzales (2007) and Sinding (2003) support the previously mentioned end-of-life quality measures as they relate to successful at home palliative care programs that not only met the patient and family needs but also proved to save health care dollars by reducing hospitalizations while meeting the patient and family care expectations which increased their overall satisfaction.

Another significant area, in terms of quality measures, is how satisfied are patients, but more realistically, family members or bereaved with the implementation of those end-of-life quality measures. According to the National Hospice and Palliative Care Organization (NHPCO), roughly 90 percent of current satisfaction surveys for end of life care are done post mortem and are filled out by the bereaved. Essentially, the survey measures the bereaved person's satisfaction level, on behalf of the decedent; with services and how well they felt the end-of-life quality measures were met. Three such articles discuss the results of post mortem survey results from the perspective of the bereaved. Fakhoury (1998), Morss, Shugarman, Lorenz, Mularski, and Lynn (2008) and Hays and Arnold (1986) talk about end-of-life care being delivered to not only the patient but the family as well. In fact, all three studies state that the patient and family are view as one unit. This outlook is effective, according to the studies, because the whole family is affected by the decline and death of a loved one. This meets the needs of not only the patient

but of the family as well. The conundrum they have discovered, however, is when it is time to measure the services with a satisfaction survey. They are only asking the bereaved whose answers mental health issues can affect. Fakhoury cites that “bereaved people are also reported to be susceptible to various psychological and emotional disturbances” as taken from articles Seale (1990), Maddison and Viola (1968) and Parkes (1965). These disturbances are depicted as recalling negative experiences over positive ones; post mortem depression, if the death of the loved one was peaceful, and the bereaved person’s own physical health. These researchers suggest that the bereaved cannot be the only gauge for quality measures at end of life.

Hanson, Danis and Garrett (1997) and Engel, Kiely and Mitchell (2006) approach quality measures in their research from the perspective of the caregivers. Even though Hanson et al., (1997) study is focused on the bereaved and Engel et al., (2006) on family members of patients with dementia in a nursing home, the results are very similar. Both groups were identified as feeling left out of any health care decision making regardless of having a living will that designated them as health care proxy. Greater satisfaction was noted for those who were involved, from the beginning, in discussions about health care goals and desires. Other measures that affected satisfaction in both studies was amount of pain and symptom management techniques, compassionate and honest information about disease process, time health care providers spent with loved ones and their access to the physician and the time spent with the family. The physician was one area of consistent concern because families felt the physician was hard to reach and very rushed during visits.

A limitation of this study is that the subjects were defined as 80 percent white and that family informants may not always reflect the opinions of the dying patient. Family may be more critical of care and may perceive more pain and suffering than the patient actually experiences.

The last three studies are the only research that could be found that either considers quality end-of-life from the patient's perspective or analyses the end-of-life preferences of the patient and the family to measure congruency. The research performed by Singer, Martin and Kelner (1999) focuses on the patient experience. These patients identified key measures as receiving adequate pain and symptom management, avoiding being kept alive after functional status is gone, having control of their end-of-life decisions, having a proxy who is willing to follow their wishes and not being a burden to loved ones. Similarly, the studies performed by Downey, Engelberg, Curtis, Lafferty and Patrick (2009) and Luptak (2006) support the above quality measures with the addition of spending time with family, maintaining dignity, having human touch and being at peace with dying. In the Downey et al. study the findings were consistent with patient and non-patient subject groups, however, the Luptak study indicates similar quality measure goals between patients and family members if they had talked about those goals prior to patient becoming ill. If they were not discussed, family members preferred more aggressive care and had not even considered end-of-life quality measures. It took them a significant amount of time to become in tune with the patient.

While all of the discussed research studies are valuable in defining quality measures of end-of-life care and tools to gauge the satisfaction with those measures,

it fails to focus on the professional medical and non-medical staff that cares for individuals at end-of-life. This paper will address the relationship between medical and non-medical staff views in regard to end-of-life quality measures in one specific metropolitan hospice program.

Conceptual Framework

As a seasoned social worker one develops a pattern of thinking, behaving and interacting. These patterns help to define how the world is viewed and how to make sense of interactions and events that occur around us. Every individual has developed their own perspective based on life experiences and since those experiences are all so different so are the perspectives. Most perspectives can be attributed to a combination of theories to develop that individual's conceptual framework. This researcher will define the conceptual framework so that the research can be understood.

Theoretical Lens

Theoretical lenses are important to research so that the researcher has a frame of reference on which to base the study. The lenses this researcher adheres to are the death and dying theory described by Elisabeth Kubler-Ross and the Narrative Theory. This will help define the structure and flow of the study presented. Both frameworks interweave with each other in the process of death and dying. Kubler-Ross states that there are five phases of grief and loss for both the patient and their loved ones. The first is denial-isolation that is marked by denying reality, rationalizing, blocking out or hiding from the truth. Anger is the second stage that is described as lashing out at anything or anyone instead of facing

the truth of death. The third is bargaining that is filled with “If only I.....then.....” statements. Depression marks the fourth stage and is described by sadness and regret. It also marks the preparation to separate from a loved one and to say goodbye. Lastly is acceptance that describes the person as calm but slowly withdrawing from the world or from the dying patient. Amongst this framework is the narrative theory marked by the patient or loved ones stories of life together and validating the importance of the other person in their life. It includes discussion about their lives and how that life was significant to others. It’s how those individuals describe their life story and how the dying persons presence was interwoven with their own. These stories are important for the dying person for reasons of leaving a legacy and to state their significance to the world. It is also equally as important to the ones left behind to reframe memories, build new memories and to stress the importance of the dying person. It is a way to assist with the acceptance phase as stories can help people to say goodbye.

Professional Lens

From the professional lens this researcher looks to the ten principles of social work for social justice as defined by the NASW Code of Ethics. Even though all ten principles are important this researcher, she has adhered to human dignity, community and the common good, rights and responsibilities and priority for the poor and vulnerable. These principles have been ingrained in all aspects of her work at the micro level, and at times, the mezzo level. She has not had much opportunity to experience macro level social work even though every aspect of her work is affected by it. She has stood by the notion that everyone deserves personal

dignity and to have his or her basic needs met. It is also the responsibility of each human to ensure that dignity and needs are protected. In her work with older, vulnerable adults she has witnessed exploitation by others. This researcher had to advocate on behalf of this vulnerable population.

Personal Lens

This researcher has had extensive exposure to death and dying over the years in two St Paul nursing homes, two St Paul hospice programs, an St Paul hospital and primary caregiver for her mother until death. It was of interest that this researcher had never really worked with death and dying during her undergraduate school years, and in fact, had worked with adolescents the entirety of that time. It was only after graduation and a non social work related job did she begin her long career with the aged, hospice patients and chronically ill individuals. In all of the years, this worker had heard hundreds upon hundreds of stories told by both the patient and caregiver on the significance of their life and by the priorities they had lived. They also shared how those views had changed over time in relation to their health care wishes at end of life. This researcher has also witnessed over the years how priorities and wishes were not honored either by ignoring them or by failing to hear them. Often times it is the professional staff that cares for these patients who fail to hear the wishes. This researcher believes that by surveying both medical and non-medical staff there will be an obvious discrepancy between the groups when they prioritize quality measures according to their own personal views.

Methods

Sample

The participants in this quantitative study include all medical and non-medical staff of one particular hospice and palliative care program in the St Paul area which numbers at about 121 people. The staff received their survey through an email invitation. The survey was preceded by recruitment letter and informed consent information. The staff submitted anonymous responses through the online Qualtrics Survey.

Measures

In an attempt to compare medical versus non-medical professional staff views of care, this researcher used an anonymous survey to incorporate the FAMCARE scale, the Family Evaluation of Hospice Care survey and the research literature to develop a list of most commonly recognized end-of-life quality measures. Eighteen measures were listed and the respondents are asked to rate them on a five point Likert scale.

Currently, the surveys that exist to gauge end of life quality measures are satisfaction surveys. One such survey is the FAMCARE survey that is comprised of twenty-one questions that are geared toward the bereaved in regards to the care received by a loved one. It asks the person to rate how satisfied they were with each item on a scale of very satisfied, satisfied, undecided, dissatisfied and very dissatisfied. The other survey used is the Family Evaluation of Hospice Care that has ten identified sections A through J. Each section has a different amount of questions

and the bereaved is instructed to answer the questions based on his or her experience and the perceived decedent's experience while under the care of hospice. Some of the questions are simple yes/no answers while others require a range answer of always, usually, sometimes and never or very confident, fairly confident or not confident or excellent, very good, good, fair and poor. The literature supports the quality measures used in the FAMCARE and Family Evaluation of Hospice Care surveys.

The survey administered takes quality measure themes from both surveys and the literature reviewed to create an end-of-life quality measures list. This list is comprised of eighteen questions based on a five point Likert scale. The answers range from "not at all important" to "extremely important." In addition to the five point Likert scale, the survey also includes two yes/no questions pertaining to end of life measures. It concludes with a free text area to offer up any other comments that the individual deems important to share. After the free text is three questions pertaining to demographics of the person completing the survey.

Included in this process was approval by two Institutional Review Boards, the University of St. Thomas and St. Catherine's University and the HealthEast Care System. HealthEast Care System has approved the research. The process for the IRB at the University of St. Thomas/St. Catherine University is also approved.

Protection of Human Subjects

Recruitment Process

A recruitment letter (Appendix F) was emailed to all existing hospice and palliative care staff and describes the content of the survey, the length of time to

complete the survey and information about informed consent. This recruitment letter was sent out three days before the survey. Four days after the survey was sent to the potential participants an email was sent out reminding them to complete the survey. See Appendix E.

Confidentiality

To ensure anonymity the recruitment letter, the survey and the follow up reminder were exactly the same for each potential respondent without any identifying marks, letters or numbers and were administered through Qualtrics Survey that protects the participant's identity. All online surveys, as well as any data collection notes and charts, was stored on the researcher's computer with a protected password. All paper records were stored in a locked drawer at the researcher's home.

Informed Consent

Each potential participant was sent a letter of informed consent with the recruitment letter as well as with the survey itself. Reviewed in this letter was an invitation to participate, background information on the purpose of the survey, the procedure they need to follow to complete the survey, and risks or benefits of being involved in the study, confidentiality, voluntary nature of participation and contact information, should they have any questions.

See Appendix B for Letter of Informed Consent.

Data Collection Instrument

All hospice and palliative care staff received an anonymous survey. The first eighteen elements of the survey consisted of questions using a five point Likert scale

for answers. These eighteen questions pertained to end-of-life quality measures. The Likert scale ranges from “not at all important” to “extremely important.” The eighteen quality measures were identified from the literature review, FAMCARE survey and the Family Evaluation of Hospice Care survey as being the most commonly used metrics. Following the eighteen measures were two yes or no questions pertaining to quality measures. Following the quality measures segment was an open text for any other comments that the respondent deemed important to share. To finish the survey was three general demographic questions about age, years of service and what group the respondent identifies with, medical versus non-medical staff. The survey is referenced in Appendix C.

Data Analysis Plan

Using chi-square analysis the researcher indicates a strong or weak central tendency based on the standard deviation. In addition, the researcher used chi-square to determine if the two groups, medical versus non-medical, are statistically different from each other in regards to quality measures. Other tests were run based on individual quality measures in relation to medical versus non-medical group identification. These tests were in the form of chi-square as well.

Findings

The current study explores the relationship between medical versus non-medical hospice and palliative care staff in regards to their views on end-of-life quality measures. The researcher conducted an anonymous on line survey through Qualtrics survey engine to determine how end-of-life quality measures are viewed by medical and non-medical hospice and palliative care professionals. They were

asked to complete the first eighteen questions as if they were the patients at end of life. One hundred and twenty one hospice and palliative care medical and non-medical staff was surveyed. Eighty-three surveys were opened but not started. Sixty-five of the surveys were started and 35 were completed even they may not have answered every questions.

The first set of findings was a breakdown of the survey questions informing percentage of responses to answered fields. It also identified the number of respondents for each question and the mean and standard deviation for each question. Also in the description of each question are minimum and maximum values and variance. Attached to each question is a set of graphs as well.

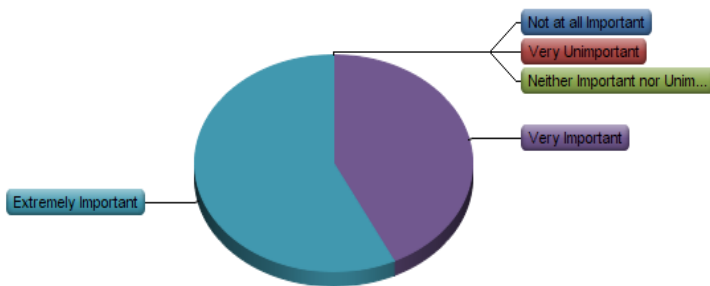
The second set of findings is a break down of questions by themes and these questions are compared to the two groups of hospice and palliative care medical and non-medical staff by way of chi-square. Each cross tabulation results in a chart that identifies the chi-square value, the degree of freedom and the p-value for the set of themed questions in relation to medical versus non-medical hospice and palliative care professionals. The cross tabulation chart describes the mean for each individual question and for the total number of respondents under their identified status, medical versus non-medical. It also denotes the number of responses under each possible answer. For instance, Table 1 identifies the mean for each answer in relation to the identified group. For example, in regard to the first question, six medical staff answered very important and eight answered extremely important and the mean for these responses is 27.57. The non-medical staff answered three for very important and four for extremely important and the mean for these

responses is 27.57. The chart also identifies the mean for a total of answers in relation to a particular answer. Very important for question one had six very important from medical staff and three for very important from non-medical staff for a mean of 1.33. For this particular question the means are identical but in the following questions the mean will have differing values.

The final set of findings is in a narrative context. This is the part of the survey that asked for any thoughts or feeling about quality measures. These will be in the original narrative quote.

Figure 1 below denotes the responses to question one of the survey. Forty-three percent of respondents answered very important and 57 percent of the respondents answered extremely important. Twenty-one respondents answered this question. Mean was 27.57 and the standard deviation was 0.51.

1. Receive adequate information about medications and the side effects.

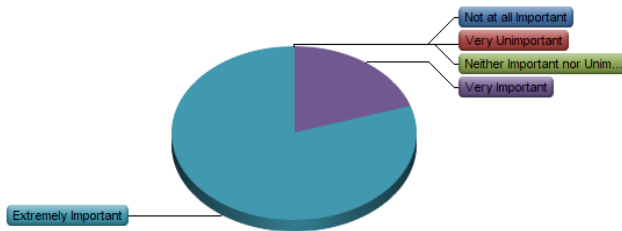


#	Answer	Bar	Response	%
24	Not at all Important		0	0%
25	Very Unimportant		0	0%
26	Neither Important nor Unimportant		0	0%
27	Very Important	<div style="width: 43%;"></div>	9	43%
28	Extremely Important	<div style="width: 57%;"></div>	12	57%
	Total		21	

Statistic	Value
Min Value	27
Max Value	28
Mean	27.57
Variance	0.26
Standard Deviation	0.51
Total Responses	21

Figure 2 below denotes the responses to question two of the survey. It appears that three individuals did not respond to this question. Twenty percent of the respondents answered very important and 50 percent of the respondents answered extremely important. The mean was 9.80 and standard deviation was 0.17. Twenty of the 23 who opened this question responded to it.

2. Attain symptom relief according to your personal values.

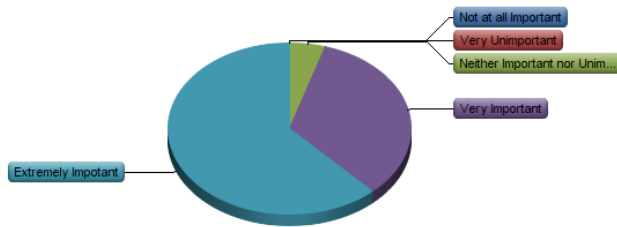


#	Answer	Bar	Response	%
6	Not at all Important		0	0%
7	Very Unimportant		0	0%
8	Neither Important nor Unimportant		0	0%
9	Very Important	<div style="width: 20%;"></div>	4	20%
10	Extremely Important	<div style="width: 80%;"></div>	16	80%
	Total		20	

Statistic	Value
Min Value	9
Max Value	10
Mean	9.80
Variance	0.17
Standard Deviation	0.41
Total Responses	20

Figure 3 below denotes the responses to question three in the survey. Five percent of the respondents answered neither important nor unimportant. Thirty-three percent of the respondents answered very important and 62 percent of the respondents answered extremely important. The mean is 4.57 and the standard deviation is 0.60. There were 21 respondents to this question.

3. Information about your prognosis.

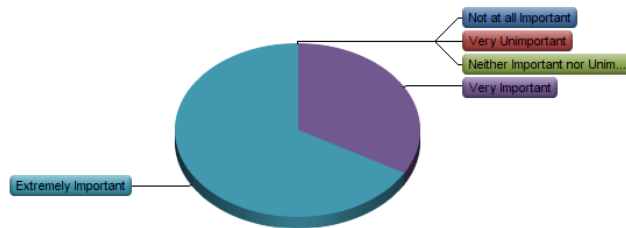


#	Answer	Bar	Response	%
1	Not at all Important		0	0%
2	Very Unimportant		0	0%
3	Neither Important nor Unimportant		1	5%
4	Very Important		7	33%
5	Extremely Important		13	62%
	Total		21	

Statistic	Value
Min Value	3
Max Value	5
Mean	4.57
Variance	0.36
Standard Deviation	0.60
Total Responses	21

Figure 4 below denotes the responses to question four in the survey. Thirty-three percent of the respondents answered very important and 67 percent of the respondents answered as extremely important. The mean is 4.67 and the standard deviation is 0.48. There were a total of 21 respondents.

4. Involvement in your plan of care.

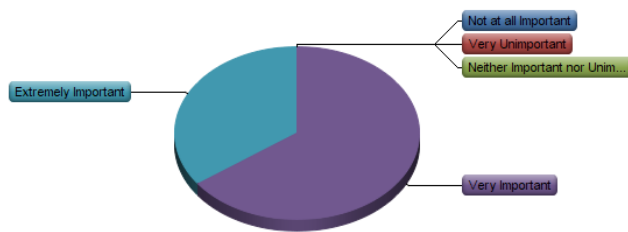


#	Answer	Bar	Response	%
1	Not at all Important		0	0%
2	Very Unimportant		0	0%
3	Neither Important nor Unimportant		0	0%
4	Very Important	<div style="width: 33%;"></div>	7	33%
5	Extremely Important	<div style="width: 67%;"></div>	14	67%
	Total		21	

Statistic	Value
Min Value	4
Max Value	5
Mean	4.67
Variance	0.23
Standard Deviation	0.48
Total Responses	21

Figure 5 below denotes the responses to question five of the survey. Sixty-five percent of the respondents answered very important and 35 percent of the respondents answered extremely important. The mean was 4.35 and the standard deviation is 0.49. The total number of respondents for this question was 20 individuals.

5. Family involvement in your plan of care.

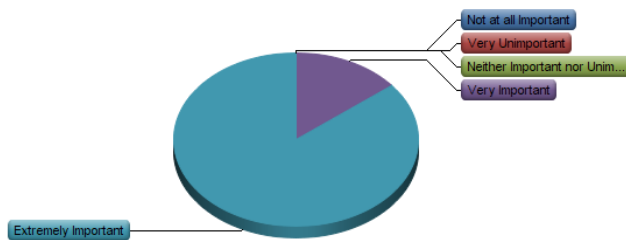


#	Answer	Bar	Response	%
1	Not at all Important		0	0%
2	Very Unimportant		0	0%
3	Neither Important nor Unimportant		0	0%
4	Very Important		13	65%
5	Extremely Important		7	35%
	Total		20	

Statistic	Value
Min Value	4
Max Value	5
Mean	4.35
Variance	0.24
Standard Deviation	0.49
Total Responses	20

Figure 6 below denotes responses to question six of the survey. Fourteen percent of the respondents answered very important to the question and 86 percent of the respondents answered extremely important. The mean was 4.86 and the standard deviation was 0.36. Twenty-one individuals responded to this question.

6. Consistent and accurate information.

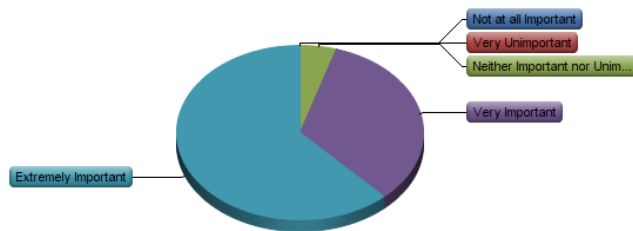


#	Answer	Bar	Response	%
1	Not at all Important		0	0%
2	Very Unimportant		0	0%
3	Neither Important nor Unimportant		0	0%
4	Very Important	<div style="width: 14%;"></div>	3	14%
5	Extremely Important	<div style="width: 86%;"></div>	18	86%
	Total		21	

Statistic	Value
Min Value	4
Max Value	5
Mean	4.86
Variance	0.13
Standard Deviation	0.36
Total Responses	21

Figure 7 below denotes the responses to question seven of the survey. Five percent of the respondents answered neither important nor unimportant. Thirty percent of the respondents answered very important and 62 percent of the respondents answered extremely important. The mean is 4.57 and the standard deviation was 0.60. Twenty individuals responded to this question.

7. Responsiveness to your emotional needs.

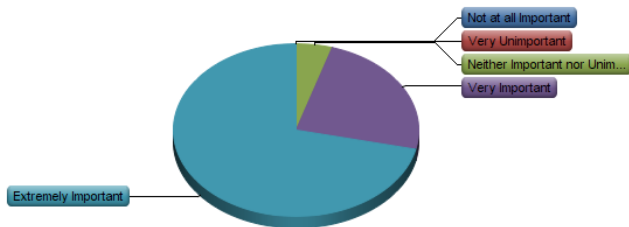


#	Answer	Bar	Response	%
1	Not at all Important		0	0%
2	Very Unimportant		0	0%
3	Neither Important nor Unimportant	<div style="width: 5%;"></div>	1	5%
4	Very Important	<div style="width: 33%;"></div>	7	33%
5	Extremely Important	<div style="width: 62%;"></div>	13	62%
Total			21	

Statistic	Value
Min Value	3
Max Value	5
Mean	4.57
Variance	0.36
Standard Deviation	0.60
Total Responses	21

Figure 8 below denotes the responses to question eight of the survey. Five percent of the respondents answered neither important nor unimportant. Twenty-four percent of the respondents answered very important. Seventy-one percent of the respondents answered extremely important. The mean was 17.67 and the standard deviation was 0.58. Twenty-one individuals responded to this question.

8. Treat the whole person, not just the disease.

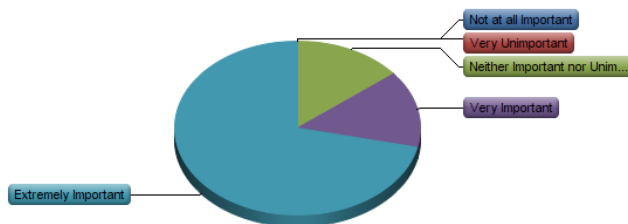


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		1	5%
17	Very Important		5	24%
18	Extremely Important		15	71%
	Total		21	

Statistic	Value
Min Value	16
Max Value	18
Mean	17.67
Variance	0.33
Standard Deviation	0.58
Total Responses	21

Figure 9 below denotes responses to question nine of the survey. Fourteen percent of the respondents answered neither important nor unimportant. Fourteen percent of the respondents answered very important and 71 percent of the respondents answered extremely important. The mean was 22.57 and the standard deviation was 0.75. Twenty-one individuals responded to this question.

9. Acknowledges and respects your personal beliefs.

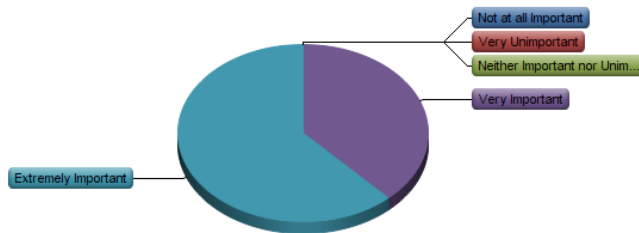


#	Answer	Bar	Response	%
19	Not at all Important		0	0%
20	Very Unimportant		0	0%
21	Neither Important nor Unimportant	■	3	14%
22	Very Important	■	3	14%
23	Extremely Important	■	15	71%
	Total		21	

Statistic	Value
Min Value	21
Max Value	23
Mean	22.57
Variance	0.56
Standard Deviation	0.75
Total Responses	21

Figure 10 below denotes the responses to question ten in the survey. Thirty-eight percent of the respondents answered very important. Sixty-two percent of the respondents answered extremely important. The mean was 17.62 and the mean was 0.50. Twenty-one individuals responded to this question.

10. Having timely access to care team (RN, Social Worker, Chaplain, Home Health Aide)

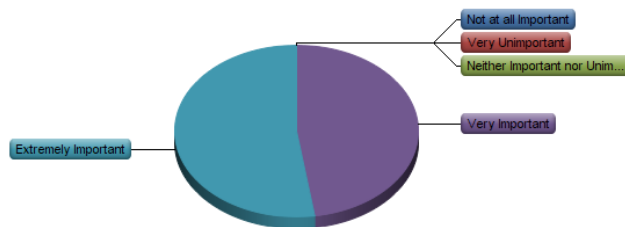


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		0	0%
17	Very Important	<div style="width: 38%;"></div>	8	38%
18	Extremely Important	<div style="width: 62%;"></div>	13	62%
	Total		21	

Statistic	Value
Min Value	17
Max Value	18
Mean	17.62
Variance	0.25
Standard Deviation	0.50
Total Responses	21

Figure 11 below denotes the responses to question eleven in the survey. Forty-eight percent of the respondents answered very important to this question. Fifty-two percent of the respondents answered extremely important. The mean was 17.52 and the standard deviation was 0.51. A total of 21 individuals responded to this question.

11. Enough details to fully understand your illness.

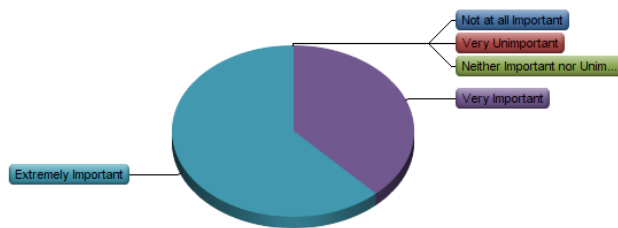


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		0	0%
17	Very Important		10	48%
18	Extremely Important		11	52%
	Total		21	

Statistic	Value
Min Value	17
Max Value	18
Mean	17.52
Variance	0.26
Standard Deviation	0.51
Total Responses	21

Figure 12 below denotes the responses to question twelve on the survey. Thirty-eight percent of the respondents answered very important. Sixty-two percent of the respondents answered extremely important. The mean was 17.62 and the standard deviation was 0.50. The total number of respondents was 21 individuals.

12. Confidence in your care team.

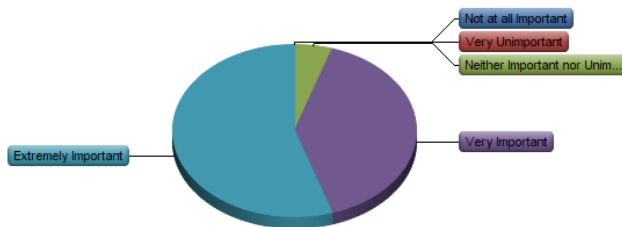


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		0	0%
17	Very Important		8	38%
18	Extremely Important		13	62%
	Total		21	

Statistic	Value
Min Value	17
Max Value	18
Mean	17.62
Variance	0.25
Standard Deviation	0.50
Total Responses	21

Figure 13 below denotes the responses to question thirteen of the survey. Five percent of the respondents answered neither important nor unimportant. Forty percent of the respondents answered very important. Fifty-five percent of the respondents answered extremely important. The mean was 17.50 and the standard deviation was 0.61. A total of 20 respondents answered this question.

13. Open communication about changes seen in your condition.

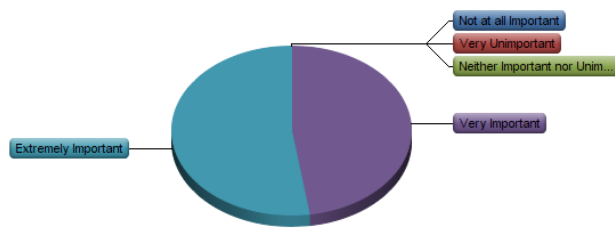


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		1	5%
17	Very Important		8	40%
18	Extremely Important		11	55%
	Total		20	

Statistic	Value
Min Value	16
Max Value	18
Mean	17.50
Variance	0.37
Standard Deviation	0.61
Total Responses	20

Figure 14 below denotes the responses to question fourteen on the survey. Forty-eight percent of the respondents answered very important. Fifty-two percent of the respondents answered extremely important. The mean was 17.52 and the standard deviation was 0.51. A total of 21 respondents answered this question.

14. Confidence in understanding the dying process.

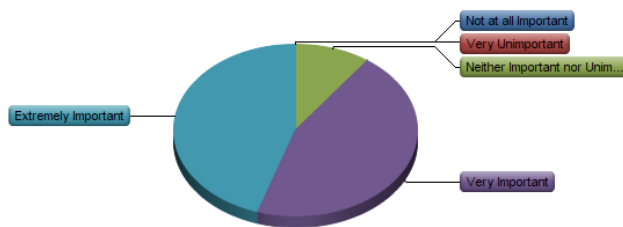


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		0	0%
17	Very Important		10	48%
18	Extremely Important		11	52%
	Total		21	

Statistic	Value
Min Value	17
Max Value	18
Mean	17.52
Variance	0.26
Standard Deviation	0.51
Total Responses	21

Figure 15 below denotes the responses to question fifteen on the survey. Ten percent of the respondents answered neither important nor unimportant. Forty-five percent of the respondents answered very important and 45 percent of the respondents answered extremely important. The mean was 17.35 and the standard deviation was 0.67. A total of 20 respondents answered this question.

15. Your spiritual needs are being met.

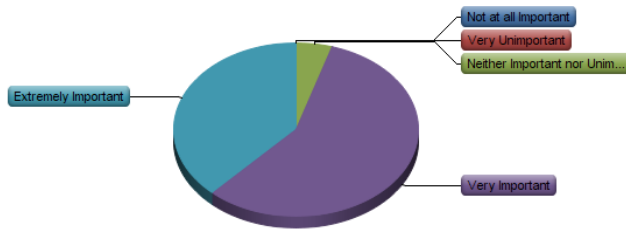


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant	<div style="width: 10%; height: 10px; background-color: #4CAF50;"></div>	2	10%
17	Very Important	<div style="width: 45%; height: 10px; background-color: #9C27B0;"></div>	9	45%
18	Extremely Important	<div style="width: 45%; height: 10px; background-color: #2196F3;"></div>	9	45%
Total			20	

Statistic	Value
Min Value	16
Max Value	18
Mean	17.35
Variance	0.45
Standard Deviation	0.67
Total Responses	20

Figure 16 below denotes responses to question sixteen of the survey. Five percent of the respondents answered neither important nor unimportant. Fifty-seven percent of the respondents answered very important and 38 percent of the respondents answered extremely important. The mean was 17.33 and the standard deviation was 0.58. A total of 21 respondents answered this question.

16. Your care team is consistently the same.

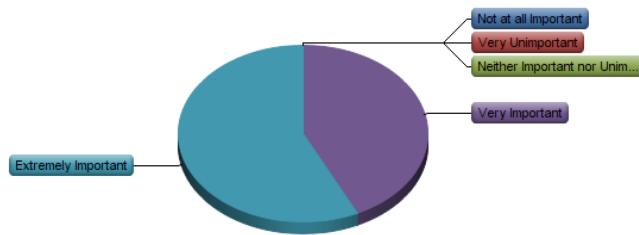


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		1	5%
17	Very Important		12	57%
18	Extremely Important		8	38%
	Total		21	

Statistic	Value
Min Value	16
Max Value	18
Mean	17.33
Variance	0.33
Standard Deviation	0.58
Total Responses	21

Figure 17 below denotes responses to question seventeen of the survey. Forty-three percent of the respondents answered very important. Fifty-seven percent answered extremely important. The mean was 17.57 and the standard deviation was 0.51. A total of 21 respondents answered this question.

17. Availability of knowledgeable staff on evenings and weekends.

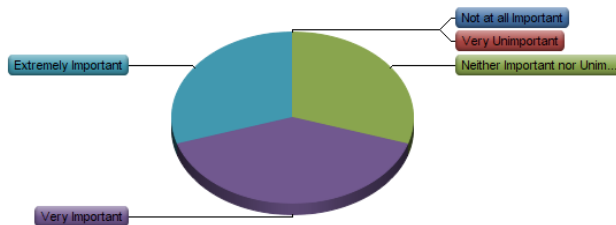


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant		0	0%
17	Very Important	<div style="width: 43%;"></div>	9	43%
18	Extremely Important	<div style="width: 57%;"></div>	12	57%
	Total		21	

Statistic	Value
Min Value	17
Max Value	18
Mean	17.57
Variance	0.26
Standard Deviation	0.51
Total Responses	21

Figure 18 below denotes the responses to question eighteen of the survey. Thirty percent of the respondents answered neither important nor unimportant. Forty percent of the respondents answered very important and 30 percent of the respondents answered extremely important. The mean was 17.00 and the standard deviation was 0.79. A total of 20 respondents answered this question.

18. To remain home until death.

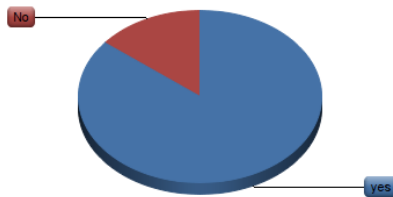


#	Answer	Bar	Response	%
14	Not at all Important		0	0%
15	Very Unimportant		0	0%
16	Neither Important nor Unimportant	<div style="width: 30%; height: 10px; background-color: #4CAF50;"></div>	6	30%
17	Very Important	<div style="width: 40%; height: 10px; background-color: #9C27B0;"></div>	8	40%
18	Extremely Important	<div style="width: 30%; height: 10px; background-color: #00BCD4;"></div>	6	30%
	Total		20	

Statistic	Value
Min Value	16
Max Value	18
Mean	17.00
Variance	0.63
Standard Deviation	0.79
Total Responses	20

Figure 19 below denotes responses to the corresponding question. Eighty-six percent of the respondents answered yes to discussing quality measures with their patients and families. Fourteen percent of the respondents answered no to discussing quality measures with their patients and families. A total of 35 respondents answered this survey question.

19. Do you discuss these measures with your hospice or palliative patients?

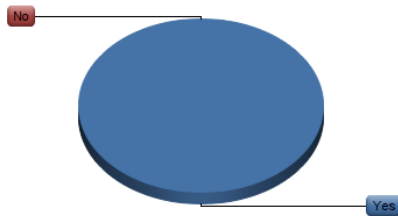


#	Answer	Bar	Response	%
1	yes	<div style="width: 86%; background-color: #4F81BD;"></div>	30	86%
2	No	<div style="width: 14%; background-color: #C0392B;"></div>	5	14%

Statistic	Value
Min Value	1
Max Value	2
Total Responses	35

Figure 20 below denotes the responses to the corresponding question. One hundred percent of the respondents answered yes to the importance of quality measures being discussed with their patients and families. The mean was 1.00 and the standard deviation was 0.00. A total of 21 respondents answered this question.

20. Do you think these are important measures to be discussed with your patients?

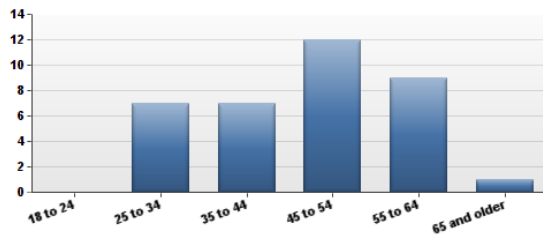


#	Answer	Bar	Response	%
1	Yes	<div style="width: 100%; height: 10px; background-color: blue;"></div>	21	100%
2	No	<div style="width: 0%; height: 10px; background-color: red;"></div>	0	0%
Total			21	

Statistic	Value
Min Value	1
Max Value	1
Mean	1.00
Variance	0.00
Standard Deviation	0.00
Total Responses	21

Figure 21 below denotes the distribution of the respondents age.

21. Age?

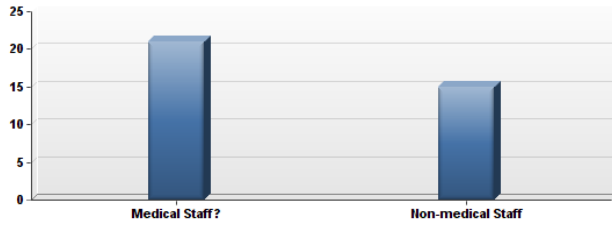


#	Answer	Bar	Response	%
1	18 to 24		0	0%
2	25 to 34	■	7	19%
3	35 to 44	■	7	19%
4	45 to 54	■	12	33%
5	55 to 64	■	9	25%
6	65 and older	■	1	3%

Statistic	Value
Min Value	2
Max Value	6
Total Responses	36

Figure 22 below shows the categories that the respondents identify with.

22. Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.

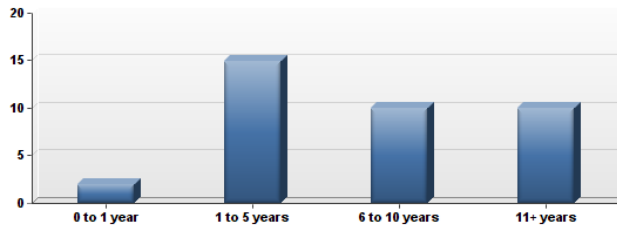


#	Answer	Bar	Response	%
1	Medical Staff?		21	58%
2	Non-medical Staff		15	42%

Statistic	Value
Min Value	1
Max Value	2
Total Responses	36

Figure 23 shows the years of service at this agency. A total of 36 respondents answered this question.

23. How long have you worked for this agency?



#	Answer	Bar	Response	%
1	0 to 1 year		2	6%
2	1 to 5 years		15	42%
3	6 to 10 years		10	28%
4	11+ years		10	28%

Statistic	Value
Min Value	1
Max Value	4
Total Responses	36

Table 1 below compares hospice and palliative medical versus non-medical staff personal views about the importance of the information shared with them as if they were the patient receiving care. The cross tabulation is broken down by question. See first set of findings to identify how each set of questions were broken down by answers and percentages. This cross tabulation also includes the mean for each response or each identified group of staff.

Table 1. Information Given to Hospice/Palliative Patients.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.			
		Medical Staff?	Non-medical Staff	Mean	Total
Receive adequate information about medications and the side effects.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	6	3	1.33	9
	Extremely Important	8	4	1.33	12
	Mean	27.57	27.57	-	-
	Total	14	7	-	21
Information about your prognosis.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	1	2.00	1
	Very Important	5	2	1.29	7
	Extremely Important	9	4	1.31	13
	Mean	4.64	4.43	-	-
	Total	14	7	-	21
Consistent and accurate information.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	1	2	1.67	3
	Extremely Important	13	5	1.28	18
	Mean	4.93	4.71	-	-
	Total	14	7	-	21
Enough details to fully understand your illness.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	6	4	1.40	10
	Extremely Important	8	3	1.27	11
	Mean	17.57	17.43	-	-
	Total	14	7	-	21

Table 2 indicates four separate chi-square tests. The first chi-square was run to compare adequate information about medications and side effects to whether the person was medical or non-medical staff. The p-value was 1.0 and the degree of freedom was 4. The second chi-square test in table 2 was run to compare information about your prognosis to whether the person was medical or non-medical staff. The p-value was 0.74 and the degree of freedom was 4. The third chi-square test in table 2 was run to compare consistent and accurate information to whether the person was medical or non-medical staff. The p-value was 0.82 and the degree of freedom was 4. The fourth chi-square test in table 2 was run to compare enough details to fully understand your illness to whether the person was medical or non-medical. The p-value was 0.96 and the degree of freedom was 4. All four chi-square tests were not statistically significant when comparing the importance of the information given to hospice and palliative patients to staff that were medical or non-medical.

Table 2. Chi-square for Information Given to Hospice/Palliative Patients

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Receive adequate information about medications and the side effects.	Chi Square	0.02*
	Degrees of Freedom	4
	p-value	1.00

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Information about your prognosis.	Chi Square	2.00*
	Degrees of Freedom	4
	p-value	0.74

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Consistent and accurate information.	Chi Square	1.56*
	Degrees of Freedom	4
	p-value	0.82

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Enough details to fully understand your illness.	Chi Square	0.64*
	Degrees of Freedom	4
	p-value	0.96

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

Table 3 below compares hospice and palliative medical versus non-medical staff personal views about the importance of listening to preferences and considering the whole person when treating the patient. The responses are from the viewpoint as if the staff were the patient. The cross tabulation is broken down by question. See first set of findings to identify how each set of questions were broken down by answers and percentages. This cross tabulation also includes the mean for each response or each identified group of staff.

Table 3. Personal Preference in Care Delivery

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.		Mean	Total
		Medical Staff?	Non-medical Staff		
Attain symptom relief according to your personal values.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	3	1	1.25	4
	Extremely Important	10	6	1.38	16
	Mean	9.77	9.86	-	-
	Total	13	7	-	20
Treat the whole person, not just the disease.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	1	2.00	1
	Very Important	3	2	1.40	5
	Extremely Important	11	4	1.27	15
	Mean	17.79	17.43	-	-
	Total	14	7	-	21
Acknowledges and respects your personal beliefs.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	2	1	1.33	3
	Very Important	2	1	1.33	3
	Extremely Important	10	5	1.33	15
	Mean	22.57	22.57	-	-
	Total	14	7	-	21

Table 4 indicates three separate chi-square tests. The first chi-square was run to compare attain symptom relief according to your personal values to whether the person was medical or non-medical staff. The p-value was 0.99 and the degree of freedom was 4. The second chi-square test in table 4 was run to compare treat the whole person and not just the disease to whether the person was medical or non-medical staff. The p-value was 0.71 and the degrees of freedom was 4. The third chi-square test in table 4 was run to compare acknowledges and respects your personal beliefs to whether the person was medical or non-medical staff. The p-value was 0.99 and the degree of freedom was 4. All three of the chi-square tests were not statistically significant when comparing the importance of personal preference in care delivery based questions to staff that were medical or non-medical.

Table 4. Chi-square for Personal Preference in Care Delivery

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Attain symptom relief according to your personal values.	Chi Square	0.31*
	Degrees of Freedom	4
	p-value	0.99

**Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.*

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Treat the whole person, not just the disease.	Chi Square	2.17*
	Degrees of Freedom	4
	p-value	0.71

**Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.*

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Acknowledges and respects your personal beliefs.	Chi Square	0.22*
	Degrees of Freedom	4
	p-value	0.99

**Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.*

Table 5 below compares hospice and palliative medical versus non-medical staff personal views about the importance involving the patient and the patient's family in the plan of care. The responses are from the viewpoint as if the staff were the patient. The cross tabulation is broken down by question. See first set of findings to identify how each set of questions were broken down by answers and percentages. This cross tabulation also includes the mean for each response or each identified group of staff.

Table 5. Patient and Family Involvement in Plan of Care

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.		Mean	Total
		Medical Staff?	Non-medical Staff		
Involvement in your plan of care.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	5	2	1.29	7
	Extremely Important	9	5	1.36	14
	Mean	4.64	4.71	-	-
	Total	14	7	-	21
Family involvement in your plan of care.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	10	3	1.23	13
	Extremely Important	4	3	1.43	7
	Mean	4.29	4.50	-	-
	Total	14	6	-	20

Table 6 indicates two separate chi-square tests. The first chi-square was run to compare involvement in your plan of care to whether the person was medical or non-medical staff. The p-value was 1.00 and the degree of freedom was 4. The second chi-square test in table 6 was run to compare family involvement in your plan of care to whether the person was medical or non-medical staff. The p-value was 0.96 and the degree of freedom was 4. Both chi-square tests were not statistically significant when comparing the importance of patient and family in the plan of care to staff that is medical or non-medical.

Table 6. Chi-square for Patient and Family Involvement in Plan of Care

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Involvement in your plan of care.	Chi Square	0.20*
	Degrees of Freedom	4
	p-value	1.00

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Family involvement in your plan of care.	Chi Square	0.65*
	Degrees of Freedom	4
	p-value	0.96

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

Table 7 below compares hospice and palliative medical versus non-medical staff personal views about the importance of meeting spiritual and emotional needs when treating a patient. The responses are from the viewpoint that the staff is the patient. The cross tabulation is broken down by question. See first set of findings to identify how each set of questions were broken down by answers and percentages. This cross tabulation also includes the mean for each response or each identified group of staff.

Table 7. Supporting Patient Emotional and Spiritual Needs

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.		Mean	Total
		Medical Staff?	Non-medical Staff		
Responsiveness to your emotional needs.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	1	2.00	1
	Very Important	5	2	1.29	7
	Extremely Important	9	4	1.31	13
	Mean	4.64	4.43	-	-
	Total	14	7	-	21
Open communication about changes seen in your condition.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	1	0	1.00	1
	Very Important	3	5	1.63	8
	Extremely Important	9	2	1.18	11
	Mean	17.62	17.29	-	-
	Total	13	7	-	20
Confidence in understanding the dying process.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	6	4	1.40	10
	Extremely Important	8	3	1.27	11
	Mean	17.57	17.43	-	-
	Total	14	7	-	21
Your spiritual needs are being met.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	1	1	1.50	2
	Very Important	6	3	1.33	9
	Extremely Important	6	3	1.33	9
	Mean	17.38	17.29	-	-
	Total	13	7	-	20

Table 8 indicates four separate chi-square tests. The first chi-square was run to compare responsiveness to emotional needs to whether the person was medical or non-medical staff. The p-value was 0.74 and the degree of freedom was 4. The second chi-square test in table 8 was run to compare open communication about changes in condition to whether the person was medical or non-medical staff. The p-value was 0.40 and the degree of freedom was 4. The third chi-square in table 8 was run to compare confidence in understanding the dying process to whether the person was a medical or non-medical staff. The p-value was 0.96 and the degree of freedom was 4. The fourth chi-square in table 8 was run to compare spiritual needs being met to whether the person was medical or non-medical staff. The p-value was 1.00 and the degree of freedom was 4. All four chi-square tests were not statistically significant when comparing the importance of supporting emotional and spiritual needs to staff that were medical or non-medical.

Table 8. Chi-square for Supporting Patient Emotional and Spiritual Needs

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Responsiveness to your emotional needs.	Chi Square	2.00*
	Degrees of Freedom	4
	p-value	0.74

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Open communication about changes seen in your condition.	Chi Square	4.07*
	Degrees of Freedom	4
	p-value	0.40

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Confidence in understanding the dying process.	Chi Square	0.64*
	Degrees of Freedom	4
	p-value	0.96

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Your spiritual needs are being met.	Chi Square	0.20*
	Degrees of Freedom	4
	p-value	1.00

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

Table 9 below compares hospice and palliative medical versus non-medical staff personal views about the importance of having access to consistent and knowledgeable care providers. The responses are from the viewpoint that the staff is the patient. The cross tabulation is broken down by question. See first set of findings to identify how each set of questions were broken down by answers and percentages. This cross tabulation also includes the mean for each response or each identified group of staff.

Table 9. Knowledgeable and Consistent Care Providers

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.			
		Medical Staff?	Non-medical Staff	Mean	Total
Having timely access to care team (RN, Social Worker, Chaplain, Home Health Aide)	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	5	3	1.38	8
	Extremely Important	9	4	1.31	13
	Mean	17.64	17.57	-	-
	Total	14	7	-	21
Confidence in your care team.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	4	4	1.50	8
	Extremely Important	10	3	1.23	13
	Mean	17.71	17.43	-	-
	Total	14	7	-	21
Your care team is consistently the same.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	1	0	1.00	1
	Very Important	7	5	1.42	12
	Extremely Important	6	2	1.25	8
	Mean	17.36	17.29	-	-
	Total	14	7	-	21
Availability of knowledgeable staff on evenings and weekends.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	0	0	0.00	0
	Very Important	5	4	1.44	9
	Extremely Important	9	3	1.25	12
	Mean	17.64	17.43	-	-
	Total	14	7	-	21

Table 10 indicates four separate chi-square tests. The first chi-square test in table 10 was run to compare having timely access to care team to whether the person was medical or non-medical staff. The p-value was 1.00 and the degree of freedom was 4. The second chi-square test in table 10 was run to compare confidence in care team to whether the person was medical or non-medical staff. The p-value was 0.86 and the degree of freedom was 4. The third chi-square test in table 10 was run to compare consistency of care team to whether the person was medical or non-medical staff. The p-value was 0.84 and the degree of freedom was 4. The fourth chi-square test in table 10 was run to compare availability of knowledgeable staff on evenings and weekends to whether the person was medical or non-medical. The p-value was 0.96 and the degree of freedom was 4. All four chi-square tests were not statistically significant when comparing the importance of knowledgeable and consistent care providers to staff that were medical or non-medical.

Table 10. Chi-square for Knowledgeable and Consistent Care Providers

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Having timely access to care team (RN, Social Worker, Chaplain, Home Health Aide)	Chi Square	0.04*
	Degrees of Freedom	4
	p-value	1.00

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Confidence in your care team.	Chi Square	1.32*
	Degrees of Freedom	4
	p-value	0.86

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Your care team is consistently the same.	Chi Square	1.42*
	Degrees of Freedom	4
	p-value	0.84

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
Availability of knowledgeable staff on evenings and weekends.	Chi Square	0.64*
	Degrees of Freedom	4
	p-value	0.96

*Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.

Table 11 below compares hospice and palliative medical versus non-medical staff personal views about the importance of dying at home. The responses are from the viewpoint as if the staff were the patient. The cross tabulation is broken down by question. See first set of findings to identify how each set of questions were broken down by answers and percentages. This cross tabulation also includes the mean for each response or each identified group of staff.

Table 11. Death at Home

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.			
		Medical Staff?	Non-medical Staff	Mean	Total
To remain home until death.	Not at all Important	0	0	0.00	0
	Very Unimportant	0	0	0.00	0
	Neither Important nor Unimportant	5	1	1.17	6
	Very Important	5	3	1.38	8
	Extremely Important	3	3	1.50	6
	Mean	16.85	17.29	-	-
	Total	13	7	-	20

Table 11 indicates one chi-square test. This chi-square test was run to compare death at home to whether the person was medical or non-medical staff. The p-value was 0.81 and the degree of freedom was 4. This chi-square test was not statistically significant when comparing the importance of death at home to staff that were medical or non-medical.

Table 11. Chi-square for Death at Home

		Do you identify as a medical or non-medical staff? Medical staff being an MD, RN, NP or Home Health Aide and none medical being anyone not listed.
To remain home until death.	Chi Square	1.60*
	Degrees of Freedom	4
	p-value	0.81

**Note: The Chi-Square approximation may be inaccurate - expected frequency less than 5.*

The following quotes are from hospice and palliative care staff regardless as to what group they identified with, medical versus non-medical. Again the survey question to solicit these comments is as follows, “In the area below please feel free to share any thoughts or feelings about quality measures.” Eight respondents had comments.

- I think we need to do more to ask patients and their families through the process how they feel these needs are/are not being met.
- I don't have direct contact with patients so I answered as to what I felt was important to me if my family member was in hospice.
- After doing the research I have found that quality measures and finding out what makes the patient who they are crucial to the delivery of care.
- Discussion of patient's goal is number one importance. Their goals direct the plan of care.
- It is important that each individual patient and family member understands to the best of their ability the processes that are occurring, the treatment and comfort options, and the risks and benefits of these options. Informed decisions based on the patient's and family's understanding is extremely necessary for a positive experience.
- I believe in the value of a person. We the professional are not going through the dying process. We the professional need to measure quality to know how we are doing and what we can do to improve our service to provide better care.

- Quality care is a very subjective item and is different for each patient and family.
- Physicians having longer conversations with the patient and family on the terminal diagnosis and what to expect in the months ahead.

Discussions

The focus of this survey was to determine whether hospice and palliative care medical staff viewed end-of-life quality measures differently than non-medical staff. Even though the findings are not statistically significant, the results are important in ways that are not yet quantified.

It is apparent that both medical and non-medical hospice and palliative care staff of one hospice program feel similar about the importance of quality measures and their use at the end-of-life. Both groups seemed to stress the importance of certain measures while not feeling that others are as important. An interesting finding would be Table 11 results. It would seem that these professionals value staying at home less than what was identified in the literature review. Singer, Martin and Kelner(1999), Downey, Engelberg, Curtis, Lafferty and Patrick(2009) and Luptak(2006) all site in their research that palliative care patients identify staying at home till death as one of the most important measures. Maybe the staff of this hospice differs in perspective because they are aware of the demand on family it will take to grant that wish. The rest of the quality measures identified in this study were answered very similarly to those in the studies in the literature review.

The comments made in the free text portion of the survey are also very consistent with the comments made in the literature review. This is especially true

in the research done by Conner, Spence and Smith(2005), Rhodes, Mitchell, Miller, Connor and Teno(2008) and McLaughlin, Sullivan and Hasson(2007) where the respondents of their surveys identified the themes of establishing goals that are patient driven, explaining the information about diagnosis, treatment and risks in a way that is understandable and to have physicians take the time to discuss the diagnosis and prognosis.

This researcher, as well as others in the literature review, seems to incorporate certain theoretical frameworks on which to base their study. Fortunately, it seems, that all use some form of Narrative Theory to encourage those who have experienced palliative and hospice care. The researchers encourage those respondents in their studies to engage in surveys that describe their experiences with these types of services. The results are from the perspective of the patient and family and how their stories or experiences affect the responses they give to surveys. All of those who are faced with a life limiting illness are faced with the steps as described in the book by Elisabeth Kubler-Ross. In some order, these steps occur as the patient and loved one comes to terms with end of life. Research is also affected by the researcher's story or life experiences. Quality measures are viewed through the researcher's lens of life events. The lens that the researcher wears affects all research, including this study.

Social Work Practice, Policy and Research

The implications of this study have an impact on social work practice, policy and research. With an increasing focus and acknowledgement of death and the issues surrounding death, social workers will need to be more knowledgeable about

the dying process. They will also need to be more comfortable in discussions about death and dying with their clients. These discussions will include end-of-life quality measures and how the client defines the measures. In practice, assessment skills will need to be developed around interviewing a patient who is experiencing a life limiting illness and developing strategies and techniques that can support that patient as well as the family that surrounds that patient.

Social workers are faced with policy issues surrounding death and dying as Medicare and other insurances are making it more difficult to serve those in need of end of life care under hospice and palliative services. There is an ever-increasing need for advocacy in the hospice field as Medicare makes it more difficult to qualify patients for Medicare covered hospice services. Research will need to focus on and prove that hospice and palliative services not only save healthcare dollars but also is an effective way to deliver and meet patient and family needs. End-of-life quality measures are one venue in research that can prove an effective way to deliver care.

Strengths and Limitations

A strength would be the end-of-life quality measures used in this study as these measures have been tested and proven valid by other research studies. The population surveyed in this study adds strength to the importance of quality measures when delivering hospice and palliative care. This population can be considered experts in the use of the service provided.

A limitation would be that quantitative research is defined as being value free but the end-of-life quality measures are all about values and what an individual holds important. By using a quantitative research design the results are all

numerical and assumptions are made based on those numbers with no room for detailed narrative data that could be useful in the study of end-of-life quality measures. Generalizability could be better established if this research model was replicated in a few more hospice programs in different regions of the United States or in a different country that has established hospice programs.

Future Implications

The future of research in the area of quality measures at end-of-life is crucial to further our understanding of service delivery at end of life. It is also vitally important to establish concrete facts that hospice and palliative care can actually save health care dollars while meeting the patient's and family's need for quality care. Medicare and other payer sources will only scrutinize hospice and palliative care services as they look to make cuts in the availability of their funding. Research needs to focus on proven pathways of care delivery at end of life and how these services will save dollars instead of increase expenditures as the media often points out.

References

- Adams, C.E., Bader, J. & Horn, K.V. (Feb. 2009). Timing of hospice referral: Assessing satisfaction while the patient receives hospice services. *Home Health Care Management & Practice*, 21(2), 109-116. doi:10.1177/1084822308323440
- Alkema, K., Linton, J.M., & Davies, R. (2008). A study of the relationship between self-care, compassion satisfaction, compassion fatigue, and burnout among Hospice professionals. *Journal of Social Work in End-of-Life & Palliative Care*, 4(2), 101-118. doi: 10.1080/15524250802353934
- Brumley, R., Enguidanos, S., Jaminson, P., Seitz, R., Morgenstern, N., Saito, S., . . . & Gonzalez, J. (2007). Increased satisfaction with care and lower costs: Results of a randomized trial in in-home palliative care. *Journal of American Geriatrics Society*, 55, 993-1000. doi: 10.1111/j.1532-5415.2007.01234.x
- Canadian Researchers at the End of Life Network. (2009). Canadian health care evaluation project: Patient questionnaire. http://www.thecarenet.ca/index.php?option=com_content&view=article&id=172&Itemid=96
- Casarett, D., Crowley, R., & Hirschman, K. (2003). Surveys to assess satisfaction with end-of-life care: Does timing matter? *Journal of Pain and Symptom Management*, 25(2), 128-132. doi: 10.1016/s0885-3924(02)00636-X

- Coleman-Archer, K., & Boyle, D. P. (1999). Toward a measure of caregiver Satisfaction with hospice social services. *The Hospice Journal*, 14(2), 1-15. http://www.reseachgate.net/journal/0742-969x_Hospice_Journal_The
- Connor, S.R., Teno, J., Spence, C., & Smith, N. (2005). Family evaluation of hospice care: Results from voluntary submission of data via website. *Journal of Pain and Symptom Management*, 30(1), 9-17.
doi: 10.1016/j.jpainsymman.2005.04.001
- Downey, L., Engelberg, R.A., Curtis, J.R., Lafferty, W.E., & Patrick, D.L. (2009). Shared priorities for the end-of-life period. *Journal of Pain and Symptom Mangement*, 37(2), 175-188. doi:10.1016/j.jpainsymman.2008.02.012
- Empeno, J., Raming, N.T.J., Irwin, S.A., Neleson, R.A., & Lloyd, L.S. (2013). The impact of additional support services on caregivers of hospice patients and hospice social workers. *OMEGA*, 67(1-2), 53-61.
doi: <http://dx.doi.org/10.2190/OM.67.1-2.f>
- Engel, S.E., Kiely, D.K., & Mitchell, S.L. (2006). Satisfaction with end of life care for nursing home residents with advanced dementia. *Journal of American Geriatrics Society*, 54, 1567-1572. doi:10.1111/j.1532-5415.2006.00900.x
- Engelberg, R.A., Downey, L., WEnrich, M.D., Carline, J.D., Silvestri, G.A., Dotolo, D., . . . & Curtis, J.R. (2009). Measuring the quality of end-of-life care. *Journal of Pain and Symptom Management*, 39(6), 951-971.
doi:10.1016/j.jpainsymman.2009.11.313

- Fakhoury, W.K.H. (1998). Satisfaction with palliative care: What should we be aware of? *International Journal of Nursing Studies*, 35, 171-176.
Doi:10.1016/soc20-7489(98)00026-1
- Fontaine, K. & Rositani, R. (2000). Cost, quality, and satisfaction with hospice after-hours care. *The Hospice Journal*, 15(1), 1-13.
[http://researchgate.net/journal/0742-969x Hospice Journal The](http://researchgate.net/journal/0742-969x_Hospice_Journal_The)
- Hanson, L.C., Danis, M., & Garrett, J. (1997). What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of American Geriatrics Society*, 45, 1339-1344. <http://www.americangeriatrics.org>
- Hedlund, S. (2013). Northwest cancer specialists cares: Coordinated, advocacy, resources, education and support: A palliative care program in an outpatient oncology practice. *Journal of Death and Dying*, 67(1-2), 109-113. doi: <http://dx.doi.org/10.2190/OM.67.1-2.1>
- Kennett, C. & Payne, M. (2010). Palliative care patients' experiences of healthcare treatment. *International Journal of Social Welfare*, 19, 262-271. doi: 10.1111/j.1468-2397.2009.00664.x
- Luptak, M. (2006). End-of-life care preferences of older adults and family members who care for them. *Journal of Social Work in End-of-Life & Palliative Care*, 2(3), 23-44. doi:10.1300/J457v02n03_04
- McLaughlin, D., Sullivan, K., & Hasson, F. (2007). Hospice at home service: The carer's perspective. *Support Care Cancer*, 15, 163-170.
doi: 10.1007/s00520-006-0110-1

- Meyers, J.L., & Gray, L.N. (2001). The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncology Nursing Forum*, 28(1), 73-80.
ISSN: 0190-535x
- Morss-Dy, S., Shugarman, L.R., Lorenz, K.A., Mularski, R.A., & Lynn, J. (2008). A systematic review of satisfaction with care at the end of life. *Journal of American Geriatrics Society*, 56, 124-129.
doi:10.1111/j.1532-5415.2007.01507.x
- Nolan, M.T., & Mock, V. (2004). A conceptual framework for end-of-life care: A reconsideration of factors influencing the integrity of the human person. *Journal of Professional Nursing*, 20(6), 351-360.
doi: 10.1016/j.profnurs.2004.08.007
- Rand UCLA Center for Health Policy Studies. (1986). Patient and family satisfaction with care for the terminally ill. Santa Monica, CA: Hays, R.D., & Arnold, S.
- Rhodes, R.L., Mitchell, S.L., Miller, S.C., Connor, S.R., & Teno, J.M. (2008). Bereaved family members' evaluation of hospice care: What factors influence overall satisfaction with services? *Journal of Pain and Symptom Management*, 35(4), 365-370. doi: 10.1016/j.jpainsymman.2007.12.004
- Ringdal, G.I., Jordhoy, M.S., & Kaasa, S. (2002). Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *Journal of Pain and Symptom Management*, 24(1), 53-62.
doi:10.1016/S0277-9536(02)00512-9

Singer, P.A., Martin, D.K., & Kelner, M. (1999). Quality end-of-life care. *Journal of American Medical Association*, 281(2), 163-168. <http://www.jama.com>

Teno, J.M. (2005). Measuring end-of-life care outcomes retrospectively. *Journal Of Palliative Medicine*, 8(1), 42-49. <http://www.chcr.brown.edu>

Appendix A



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1-866-326-CARE

December 17, 2013

**Institutional
Review Board**

Midway Campus
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651-232-5800
irb@healtheast.org
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Sheila Oliver
554 Vicki Lane
Shoreview, MN 55126

Dear Ms. Oliver,

Please be advised that the following study has been approved through expedited review by the HealthEast Institutional Review Board on December 17, 2013

End of Life Quality Measures

This approval includes:

- Informed Consent (Version 12.13.2013)
- Staff Survey

As the primary investigator, you are required to make periodic reports, at least annually, to the IRB. These reports shall include the number of subjects enrolled, progress to date, and an assessment of the study's overall disposition. Any proposed changes to this study that affect human subjects must be brought to the attention of the IRB prior to their initiation. An exception to this rule is any change made in an emergency situation for the protection of human subjects. All investigators are required to notify the IRB of any unanticipated event immediately.

Please reference the following HealthEast IRB number for this study in all future correspondences: **HIE 13 12 003**. Approval of this study has been granted for a period of one year and expires on December 17, 2014. You may access our website at www.healtheast.org/irb to obtain a copy of the "Project Evaluation and Review Report" form which will be used to complete your annual study review or final report. This review is due no later than November 3, 2014 for the November 17, 2014 IRB meeting.



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**Institutional
Review Board**

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If you have any questions regarding this communication, please contact our office at 651-232-5363.

The HealthEast Institutional Review Board wishes you every success with this research study.

Sincerely,

A handwritten signature in black ink that reads "Dean R. Huska".

Dean R. Huska
Chair, HealthEast Institutional Review Board

Appendix B

CONSENT FORM

UNIVERSITY OF ST. THOMAS

End of Life Quality Measures

[534458-1]

I am conducting a study about *End-of-Life Quality Measures and any differences in the way they are viewed by hospice and palliative care medical staff versus non-medical staff*. I invite you to participate in this research. You were selected as a possible participant because *you are either hospice or palliative care medical or non-medical staff of HealthEast*. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: *Sheila M Oliver, a graduate student at the School of Social Work, University of St Thomas/St Catherine University*.

Background Information:

The purpose of this study is to determine if there is a significant difference in the way hospice or palliative medical staff view end-of-life quality measures versus the views of non-medical staff.

Procedures:

If you agree to be in this study, I will ask you to do the following things: complete a survey emailed to you that will contain an eighteen item quality measure list that you will rank in order of personal importance, one being most important and eighteen being least important. You will be asked to view these items as if you were the one receiving end-of-life care. In addition, there will be two yes or no questions, an area for comments and two demographic questions. The survey is expected to take 15 to 20 minutes to complete.

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include *computer records for coded data and surveys on line*. *Computer records and online surveys will be protected by password that only the researcher will have access to*. *When the study is complete in May of 2014, all computer documents will be deleted*.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with HealthEast Hospice or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time. Should you decide to withdraw after a survey is submitted, that data will still be used as it would be impossible to determine which survey was completed by you. You are also free to skip any questions I may ask.

Contacts and Questions

My name is *Sheila M Oliver*. You may ask any questions you have now. If you have questions later, you may contact me at 651-308-3683. My advisor's name is *Dr. Felicia Sy* and her number is 651-962-5803. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

You are welcome to print a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age.

Appendix C-Survey

Please answer the following eighteen items on a scale of one to five where one is very important to you. Answer the questions as if you were receiving end-of-life care.

1) Receive adequate information about medications and their side effects

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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2) Attain symptom relief according to your personal wishes

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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3) Information about your prognosis

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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4) Involvement in your plan of care

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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5) Family involvement in your plan of care

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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6) Consistent and accurate information

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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7) Responsiveness to your emotional needs

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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8) Treats the whole person, not just the disease

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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9) Acknowledges and respects your personal beliefs

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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10) Having timely access to care team (RN, Social Worker, Chaplain, Home Health Aide)

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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11) Enough details to fully understand your illness

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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12) Confidence in your care team

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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13) Open communication about changes seen in your condition

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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14) Confidence in understanding the dying process

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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15) Your spiritual needs are being addressed

Not At All Important	Very Unimportant	Neither Important or Unimportant	Very Important	Extremely Important
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16) Your care team is consistently the same staff

Not At All	Very	Neither Important	Very	Extremely
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Important Unimportant or Unimportant Important Important

17) Availability of knowledgeable staff on evenings and weekends

Not At All Very Neither Important Very Extremely
Important Unimportant or Unimportant Important Important

18) To remain home until death

Not At All Very Neither Important Very Extremely
Important Unimportant or Unimportant Important Important

Please answer yes or no to the following questions.

1) Do you discuss these items with your hospice or palliative patients?_____

2) Do you think these are important items to discuss prior to or in the beginning of
start of care?_____

In the area below please feel free to share any thoughts or feelings about quality
measures.

Please answer the following questions.

1. Age?

18-24_____

25-34_____

35-44_____

45-54_____

55-64_____

65 and older_____

2. Do you identify as a medical or non-medical staff? Medical being an MD, RN, NP
Or Home Health Aide and non-medical being anyone else not listed.

Medical Staff?_____

Non-medical Staff? _____

3. How long have you worked for this agency?

0-1 year _____

1-5 years _____

5-10 years _____

10+ years _____

Thank you for your participation in this study and feel free to contact me with any questions you may have. My email is smoliver@healtheast.org.

Appendix D-Recruitment Letter

Dear Potential Participant,

My name is Sheila Oliver and I am a Masters student in the School of Social Work at the University of St. Thomas/St. Catherine University. Currently, I am working on my clinical research paper under the supervision on Dr. Felicia Sy, Ph.D. I am sending out surveys to hospice and palliative care professionals to determine if medical versus non-medical staff have different views in regards to end-of-life quality measures.

My study focus is on one hospice/palliative care group in the St. Paul-Minneapolis area. My goal is to send you a survey through Survey Monkey in one week to gather the data necessary to complete my research. One week after the survey is sent you will receive a reminder to complete the survey. If you have completed by then you can choose to delete the message. This message will serve as a reminder and not intended to coerce you in any way to complete the survey.

Background Information:

- The survey will take you approximately 15 to 20 minutes to complete.
- Your involvement in this survey is completely voluntary and there is no known risks or benefits to participation.
- You are invited to answer all questions or only the ones you feel comfortable answering. You may end the survey at any time you wish.
- The survey will be kept electronically until the study is complete, with your permission.
- Your survey answers will be considered confidential and protected by a

Code password.

- All electronic records and surveys will be destroyed after the study is completed in May of 2014.
- If you have any additional questions about this survey please feel free to contact me at 651-308-3683 or email at smoliver@healtheast.org or you can contact my supervisor, Dr. Felicia Sy, Ph.D., at 651-962-5803 or email at Felicia.Sy@stthomas.edu
- This study has received approval by two Internal Review Boards, one at University of St Thomas/St Catherine University and one at HealthEast Care System.
- After the surveys are complete and data collected I will submit a final paper for publication and will perform an oral report at St. Catherine University in May of 2014.

Again, I will be sending you a survey in one week through Survey Monkey that you may choose to fill out and a reminder will also be sent to you through email one week after the survey. Please do not hesitate to contact me with questions.

Thank you for your time,

Sheila Oliver, LSW

Graduate Student at the School of Social Work

University of St Thomas and St Catherine University

Appendix E-Reminder Email

One week ago you were sent a survey through Survey Monkey. I would just like to take this time to thank those of you who have completed the survey and remind those of you who wanted to complete the survey that you have one week to finish it up so that I may have time to analyze the data. Again, any questions please call me at 651-308-3683 or email me at smoliver@healtheast.org

Thank you,

Sheila Oliver

Graduate Student at the School of Social Work

University of St Thomas and St Catherine University

