Patient and caregiver satisfaction with end-of-life care: a need for instrument validity

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2009
Dedication

First and foremost I would like to dedicate this project to my Grandpa Wietmarschen, my Grandma Wietmarschen, my Father, and Doug; because of their illnesses I have learned about the amazing care of Hospice and developed an interest.

Secondly, I would like to dedicate this to my family and friends that have been there to support me with love and advice through this point in my life.
Acknowledgements

I would like to thank my advisor Linda Miller, RN, BSN, MPH for all her help and guidance in this project. She has been someone to rely on, vent to, bounce ideas off of, and constantly been a voice of optimism and comfort. I would like to thank Jolene Miller, MLS, for helping me with my research and Christopher Bork, PhD, who helped me with the statistical analysis of my paper. I would like to thank Cindy Ohms and Bridge Home Health Hospice for their cooperation. I would also like to thank my family and friends again for loving me and encouraging me when times got rough; they are the reason I have had the strength to keep going.
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Introduction

End of life care is a very sensitive and important aspect of healthcare. It is defined by the National Institutes of Health as the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and the symptoms or impairments resulting from the underlying irreversible disease that require formal (paid, professional) or informal (unpaid) care and can lead to death. Hospice has made end of life care their priority with the ultimate goal of improving the quality of life for dying patients and their families. Quality of life can be viewed in many different ways depending on what the individual patient thinks is important in their lives; Eischens refers to quality of life as, “a concept that includes social, spiritual, financial, physical, and psychological dimensions of a person’s life. Each of these domains influences a person’s well-being and overall functioning” (Eischens, Elliott, & Elliott, 1998, p. 143). Quality of life is an all encompassing view of how well the patient is functioning at their end of life. Therefore, many individuals and families turn to hospice for assistance with physical needs, symptom control, and the emotional and psychological concerns that arise in the dying patient. This can also be considered as palliative care: the total; physical, emotional, social, and spiritual; care of patients with life-threatening disease and of their families. The focus of care is both the quality of life of the patient and the support of the family and friends (Higginson, 1993). It is important to be sensitive to the unique situation and the emotional vulnerability of the dying patient and the family when evaluating the effectiveness of hospice care. However, research has shown that most individuals are cooperative and their families are grateful for the compassion and evaluation of the researchers (Davies, Reimer, Brown, & Martens, 1995). Patients want their concerns and voices to be heard in hopes that it will improve the next generation of hospice patients and their caregiver’s end of life and quality of life. Evaluating the effectiveness of
hospice care allows hospice organizations to improve and fine tune the methods of their end of life care. Satisfaction surveys sent out to patients and their caregivers is the preferred method of evaluating hospice care. These are used as feedback tools for hospice to compile and discuss, evaluate, and revise their methods of care. This evaluation process must be completed through validated and reliable research instruments in order to accurately apply the findings.

Hospice is a highly revered program that strives to provide everything necessary to help manage a patient’s terminal illness with specialized medical and nursing care, expert pain and symptom management, all necessary medications/equipment/supplies, various types of therapy, and emotional/spiritual/bereavement support for the entire family (http://www.hospicenwo.org/AboutUs.html). The vision statement of Hospice is, “to care for terminally ill patients wherever they live to provide comfort and quality of life in the final months” (http://www.hospicenwo.org/AboutUs.html). Hospice serves anyone with any type of terminal illness or progressive disease that no longer responds to curative treatment and are encouraged to seek assistance when it is believed they have a life expectancy of 6 months or less. Patients are usually referred to hospice by physicians but can also be referred by family members, friends, clergy, or other health professionals. The eligibility for services is verified by a physician and evaluated by hospice. Hospice re-evaluates their patients every 60-90 days, and as long as the patient is declining, they are re-certified for hospice care as long as they live. Most of the patients who seek hospice care have some type of cancer. Other patients who seek hospice care are in the final stages of: lung disease, heart disease, kidney disease, other neuromuscular disease, Alzheimer’s type dementias, or AIDS. Hospice patients are offered services as an in-patient or home care patient such as: palliative and end of life care, day-to-day care, respite care and grief/bereavement support for their families, spiritual/clergy support,
therapies (massage, music, art, and pets), and 24-hour visitation for in-patient. One of the advantages for hospice patients is that some hospice programs are not-for-profit United Way agencies: 70% of funding comes from insurance/Medicare/Medicaid, 20% of funding comes from various grants, and 10% of funding comes from United Way. There are a number of hospice programs that are also for-profit.

The purpose of this research project is to revise, validate, and repeat a previously completed satisfaction survey of hospice patients and their caregivers. Previous research has shown that if we can demonstrate high levels of satisfaction for hospice patients and their caregivers we can measure improved quality of life for dying patients and their caregivers (Steele, Mills, Long, & Hagopian, 2002). The task at hand is to ensure that the tools used to measure the patient and caregiver satisfaction are valid and reliable.
Literature Review

History of Satisfaction

Prior research on end of life care indicates that hospice care is well received by patients and caregivers involved in the hospice program. Steele, Mills, Long, and Hagopian (2002) concluded in their research that patients and caregivers believed their hospice care experiences were very satisfactory. Satisfaction can be measured and defined as “the evaluation based on the fulfillment of expectations” (Williams, Coyle, & Healy, 1998, p. 1351). Their research also indicated that hospice care eases pain and suffering at the end of life and improves their quality of life. However, Steele’s research was limited by not having a sensitive instrument to achieve validity and reliability. The instrument as mentioned before is often in the form of a survey that is sent out to patients and their caregivers to evaluate satisfaction with end of life care. Brasel (2007) outlines several instruments available to measure quality of life in addition to surveys: family conference, Karnofsky score, Edmonton Symptom Assessment, Memorial Symptom Assessment Scale, European Organization for Research and Treatment of Cancer, Quality and Quantity of life Questionnaire, Cambridge Palliative Assessment Schedule, and Palliative Surgery Outcome Score. Validating and making sure these instruments are reliable is a main priority when wanting to study and improve end of life care for hospice patients and their caregivers (Brasel; Walsh & Walsh, 1998; Welk & Smith, 1999). Many assume that hospice care is superior to other end of life care available to the dying patient and family. Reliable and validated studies are necessary to prove these assumptions so hospice can provide care to patients and families with confidence because the care is grounded in evidence based medicine. For example, Pevey (2005) conducted an interview with hospice patients and questioned them on how hospice has been a comfort. These patients reported that communication, human contact,
and physical attention were very comforting to them while they resided under hospice care. Of the 38 patients interviewed, only 2 had mild, individualized, negative comments about hospice. Reliable and validated research like the fore mentioned study is required to demonstrate the value of hospice care. These means of evaluating end-of-life care and quality of life issues is useful and beneficial in developing plans and assessing the achievement of hospice programs around the world (Eischens et al., 1998).

Many studies have been performed to assess the quality of life of hospice patients at the end of their life. The overwhelming majority of these studies have shown hospice to be superior in ratings of satisfaction of patients and their caregivers. Steele, Mills, Hardin, and Hussey (2005) used the Missoula-Vitas Quality of Life Index (MVQOLI) to study home care hospice patients and their perceptions on symptoms, function, interpersonal, transcendence, and well-being. The positive scores on all 5 dimensions allowed them to conclude that home care hospice patients had a good to very good quality of life. They also demonstrated with statistics that symptom control and patient function were exceptionally positive, showing that symptoms of patients were controlled well and patients were able to maintain an acceptable amount of function. However, the highest mean scores on the MVQOLI were on the dimensions of interpersonal (interactions with family and friends) and transcendence (finding a meaning and purpose of one’s life); and these are a few of the goals that hospice works hard to achieve. A similar study also shows that patients place a higher value on autonomy and privacy rather than the value of relief of suffering as their caregiver demonstrates (Terry, Olson, Wilss, & Boulton-Lewis, 2006). These studies allow hospice to mold their care to support what the family values and what the patient values at their end of life. Steele, et al, used a Likert-type instrument to survey patients and their caregivers about satisfaction with a southeastern U.S.A. Hospice. They
sought to measure satisfaction with staff, communication between patients and staff, education and information for patients and their families, service, symptom management, and satisfaction overall (Steele et al., 2002). They concluded that overall satisfaction with Hospice was rated highly by the patients and their caregivers. In this study there was one area where scores were lower than expected. This was demonstrated by symptom management and patients gave lower scores than caregivers. This discovery allowed this specific hospice to evaluate further and to work on their interventions of symptom control.

Other studies have also been performed around the world regarding the satisfaction of patients and their caregivers in hospice programs. They demonstrate that it is important that satisfaction surveys involve the patient’s comments and concerns (Higginson, 1993; McGrath, 2001). One study performed in Australia interviewed several focus groups that consisted of caregivers to deceased hospice patients. This study found that hospice was warm, friendly, caring, respectful, supportive, medically competent, and their staff had good clinical skills (McGrath). A study conducted in Northern Ireland questioned patients of hospice home care about their evaluation on referral, benefits from home care, satisfaction, and suggestions for improvement (Kernohan, Hasson, Hutchinson, & Cochrane, 2006). The Northern Ireland Hospice Day Hospice share the same goals that the U.S. Hospice values; quality of life, holistic care, continuity of care, and enabling patients to receive treatment at home if they wish. Kernohan, et al, show that patients indicate they benefited from hospice day care and feel their caregivers also benefited from hospice by receiving respite. Patients overall satisfaction with the questions on hospice were positive like most other hospice patients’ responses.

Interviewing and surveying families of patients who have passed away while in hospice care is another mainstay of evaluating satisfaction with hospice and their program. Hospice has
been conducting family surveys for over 20 years by sending out a mailed questionnaire 2-4 months after their loved one has passed away (Welk & Smith, 1999). This study reported that 97% of the families believed that their loved one was either very satisfied or satisfied with the hospice program in which they were involved. A response of 91% of families stated that hospice assisted them in managing their stress and anxiety while caring for their loved one, and 94% of families responded that they felt they were adequately educated about the training and service needed to care for the hospice patient. Another study, done by Teno, Clarridge, and Casey (2004), asked about the satisfaction of families of patients who had passed away in various settings, such as: hospital, home nursing services, home hospice services, and the nursing home. They interviewed families and asked about the quality of care at the last place the patient spent at least 48 hours. Their research stated that hospice home care patients had lower rates of unmet needs compared with the other settings of care. The family members also expressed higher satisfaction, less concerns of care, and higher emotional support from hospice home care.

There has been some discussion about a “halo effect” that happens when conducting research with hospice patients and their survived caregivers. Welk and Smith(1991) discuss how it might be hard for some caregivers to offer criticism of hospice because of their appreciation of the services, even if the patients’ needs were unmet. Another study concludes that high satisfaction rates may not mean that patients have had good experiences with hospice, but that they reflect that hospice did all they could (Kernohan et al., 2006; Williams et al., 1998). The only way to really identify if high satisfaction means good experience is to ask these questions directly in a survey to the patients so as not to confuse the results or data. These discussions pose many questions about who answered the survey, why they were so apt to not offer criticism, and is this an accurate portrayal of the satisfaction with the hospice program?
All areas of medicine are constantly being assessed, evaluated, and adapted because of research showing one treatment works better than another; this principle also applies to hospice care. Therefore, research is essential to the survival and improvement of hospice in the health care system (Ferrell, 1996). In particular, survey research on the satisfaction of patients needs to be studied to help identify potential weaknesses and strengths of the hospice program. This will allow hospice to improve and become a provider better able to serve their patients with confidence. In addition, standards of care can be established which will ensure a consistent and excellent delivery of care to patients and families. This results in improved confidence for patients, families, and the general public in hospice care. It also will result in improved staff morale and retention due to the positive reinforcement and clear direction to the delivery of end of life care that is based on evidenced based medicine (Hohl, 1994). It is a patient’s right to receive care grounded in evidence based studies. The consequences of not engaging in validated and reliable research in end of life care are undervaluing the positive impact of hospice care and potentially uneven standards and delivery of end of life care (Thyer, 1998).

*Ethical Issues: Cons*

There are many ethical issues to consider when studying and interviewing patients and caregivers at the end of life. Munhall suggests that research treats people as a means to a research end even if the research subject is expected to gain from the experience (Munhall, 1988). Katz states: “the decision to use dying patients as research subjects is one of the most controversial decisions an investigator can make” (Katz, 1972, p.375). Benoliel states, “there may be merit in raising the general question as to whether dying patients should ever properly be subjects for scientific study” (Benoliel, 1980, p.124). These statements are concerning palliative
experiments, observations, and interviews. More specifically interviews can be detrimental to the hospice patient’s health when the researcher feels a burst of power and continues the interview longer than can be tolerated by the patient. Therefore, the interview can turn into an interrogation or cross questioning (Larossa, 1981).

Moral issues are raised in the realm of palliative care research especially when concerning informed consent. Some argue that patients cannot truly give informed consent due to their illnesses and that their willingness cannot be assured. Other moral issues raised are concerns whether the patient can benefit from research at all since their lives are shortened and if the benefits they do receive fall short of the risks taken (Casarett & Karlawish, 2000). These risks and benefits may be hard to define at the end of life as they seem to change as the patient is closer to death. Patients may not want to live as long and instead value a higher quality of life without pain. Therefore, the interview or questionnaire itself may be decreasing their quality of life by performing this task when the patient would rather be spending their precious time with family member and loved ones (Casarett & Karlawish). To help define and weigh the risks and benefits three strategies have been suggested by Casarett and Karlawish. The researcher first needs to understand how patients perceive the stated risks and benefits, then the Institutional Review Board (IRB) needs to identify only the risks that are beyond those of usual care, and finally the IRB should include a palliative care professional to assist in evaluating the research. However, this is still not a proven method for decreasing and evaluating the risks and benefits placed on a patient in hospice or other palliative care setting. Lastly, one author asks the question if whether or not we should be conducting this research at all in the palliative care realm (de Raeve, 1994).
There have to be boundaries in conducting research in a field as emotionally charged as end of life care and hospice. However, many providers, IRBs, and researchers are still uncertain with the fuzzy limits and boundaries that involve dying patients (Casarett & Karlawish, 2000). Researchers need to understand that randomization to treat some patients and not treat other patients cannot be used with hospice programs, even though this is often the hallmark of an experimental design (Kovacs, 1998). Therefore, patient and family needs assessments through interviews and questionnaires are deemed the hallmark to determining the satisfaction among those involved with hospice. There is a down fall, however, because of the sensitive nature of hospice and end of life needs. Researchers must be cautious in evaluating the hospice service in order to not receive response bias, non-response due to fatigue, and the “halo effect”.

Another challenge that is posed when working with hospice patients is their physical and psychosocial well being. These patients are terminally ill and there is a high probability that they may pass away before completing the assessment fully and this leads to fewer numbers in studies which may in turn lead to a limitation in reliability and/or validity. Some researchers argue that the patients in hospice care may have a diminished decision making capacity which may make it difficult for them to answer questions on a questionnaire correctly or it may make it difficult for them to fully understand a question when interviewed (Kristjanson, Hanson, & Balneaves, 1994). Cognitive impairment is common in palliative care and the researcher must be aware of this in order to accurately use the information received from such patients. There may be a benefit to informally assessing the patients cognitive functioning before conducting an interview or handing the patient a questionnaire. There may be benefit to formally assessing the patients cognitive functioning when performing more in-depth studies. Also, researchers are concerned
whether their caregivers will benefit from assessing hospice and the care of their loved ones who have passed on or will it be a burden or an invasion to their privacy (Kovacs, 1998).

Another issue can be one concerning the staff of hospice. Casarett and Karlawish (2000) pose the question is it ethical to allow staff to be used as researchers when they are supposed to be caring for the Hospice patient and will this increase unnecessary cost to the institution? There is an ethical dilemma for researchers who are also clinicians whether or not to intervene in certain situations for the patient’s benefit or whether or not to intervene for the study’s benefit. Researchers need to be openly communicative with the IRB when conducting this type of research and when they see themselves in any of these situations. It is necessary that the IRB is educated in the medical field of palliative care in order to fully evaluate a study to be conducted. In taking these challenges into consideration the researcher must first pay attention to informed consent, freedom to withdraw, and voluntary participation with the patients involved in hospice care (Kristjanson et al., 1994). The researcher must also obtain the patient’s preferences and expectations and strive to meet these goals (Casarett & Karlawish).

Ethical Issues: Pros

However, there is a flip side to all of the consequences and concerns when working with patients in a palliative care experiment. Ethical research previously done in 1994 by Eduardo Bruera has shown that patients are not considered merely as a means to an end if the research being done is necessary. Bruera states that historically palliative care programs look at or consider results with caution due to the fact that research is not an initial component of their care programs. However, other medical programs historically do include research and evaluation as one of their components from the beginning and this makes staff more comfortable with the IRB
and these programs continue to include research and evaluation in the analysis of these programs. In order to reassure patients, caregivers, and their respective palliative care programs that evaluation research should be conducted, the research has to comply with suggested guidelines. Relevance of the research must be carefully outlined in the proposal presented to the respective parties and there must be clear answers from generated questions. Bruera (1994) found that when asked to be included in evaluation research, 80-90% of palliative care patients willingly volunteered to do so after understanding the purpose and potential benefits. In addition to explaining relevance of the research the study must also consider these issues: simple language should be used, forms should be concise, mental status should be evaluated, all staff of the palliative care program should be informed and willing to help participate in the study, and adequate time should be given to caregivers to understand and consult with the patient about the study being performed. To address an ethical con of conducting research in a palliative care program, the researcher is suggested to take into account the patient’s mental status. If the patient is not cognitively present than they should be excluded from the study trial. Another key element when discussing palliative care research is do determine if the study is absolutely necessary and if the study will yield meaningful answers to meaningful questions. Studies that seek out trivial issues should be avoided in this type of setting due to the condition of the terminally ill patients (Bruera). Those studies that are meaningful and assess major issues should absolutely be conducted. In the summary of Bruera’s study he states, “while this patient and family population is specifically vulnerable and special consideration should be taken in the design and execution of clinical trials, it would be both scientifically and ethically wrong to exclude this very ill population from research” (1994, p.7).
Benefit versus risk assessment is a key component to consider when conducting research in the palliative care realm. Research that will have a direct impact on the specific patient population and caregiver population can be conducted with consent from the respective party. The results of the research must also benefit the specific population involved in the experiment (Bruera, 1994). Previous research on hospice care has shown that the benefits to current and future hospice patients and their families far outweighs any risk of harm to current patients and their caregivers. The risks to such patients are understood to be temporary discomfort and overlying fatigue while completing surveys; in order to keep this risk to a minimum surveys are to be kept short with only pertinent information included. The risk to the caregivers are understood to be adding onto their already emotionally difficult situation.

A study by Davies, Reimer, Brown, and Martens (1995) recognized the fact that patients in end of life care have limitations on what they can perform. This study interviewed end of life patients and their families and in their final interview asked “what has it been like for you to take part in this interview”? The responses to this question showed that family members and patients found the experience to be beneficial and it compensated for the temporary discomfort. Families feel they have contributed to a valid cause when they are approached as equals and are able to share their comments and experiences. Patients are able to put into words what they feel and what they are going through, which provides them with an eye opening moment of realizing what they value and how they can improve their quality of life and their end of life.

Some researchers are still skeptical on why palliative care programs should conduct evaluation research. Other researchers have sought to show that patients and their caregivers should be included in research for various reasons. One of the primary goals of hospice and other palliative care programs is to relieve their patients suffering by any and all means possible.
In order to show that the programs are, in actuality, reaching this goal is important in determining success (Krisman-Scott & McCorkle, 2002; Mount & Scott, 1983). The best way to measure this success would be to allow the patients to give subjective assessments on the process and outcomes of the care they are receiving (Tierney, Horton, Hannan, & Tierney, 1998). This is a very direct and appropriate measure if it follows the guidelines that Bruera suggests. When taking these guidelines into account, satisfaction, symptom control, and quality of life can be reliably assessed by hospice patients (Eischens et al., 1998; Tierney et al.). Therefore, from these surveys and interviews hospice and other palliative care programs can learn, reevaluate, and improve the care provided to patients at their end of life. Results of the surveys are also important because these patients deserve to be heard just like any other patient involved in any other program with any other illness (Terry et al., 2006). If practitioners categorize terminally ill patients with non-terminally ill patients the practitioners will never be competent enough to fully care for them correctly. Patients at the end of life have different needs, desires, and opinions regarding their treatment than those who are acutely ill. Research must be conducted with this specific set of patients in order for the appropriate care to be given.

Another reason why research should be conducted in home care is because it is one of the fastest growing areas in health care today due to aging baby boomers needing more care and support (Hohl, 1994). The hospice industry is going to be accepting more patients and educating more caregivers on how to care for their loved ones. If hospice wants to continue growing and be adaptable to their patients needs, they need to conduct satisfaction surveys to accomplish this task. In addition to the growing nature of hospice, hospice has established themselves as a non-judgmental care facility that allows patients to maintain control over treatment decisions. In
order to understand the needs of the patients, assessments about satisfaction and concerns need to be conducted (Bass, 1982-3).

The staff of hospice and palliative care programs are involved in the research process as well as the researchers, caregivers, and patients. A fore mentioned ethical issue suggests that staff may not understand when to consider the patient or the study and also if they trust in the study. Hohl (1994) suggests that evaluation surveys can have a positive impact on the staff, especially when the feedback is positive. This can be received by the staff as a sense of accomplishment; a job well done. Staff retention can also be considered when positive feedback is seen on satisfaction surveys. The negative feedback from the surveys can be received by the staff as constructive criticism on how to make the lives of their patients more meaningful and less painful. One study looked at the staff point of view of conducting research and used 225 staff members from the Hospice of Bluegrass to complete a survey asking 14 questions about their thoughts on research in the facility (Kirsh et al., 2004). The surveys results indicated an overwhelming agreement on the importance of research in the hospice setting. This study also identified barriers to research that the hospice staff encountered. These barriers included: 49% stated that research was too intrusive, 48% stated that research takes too much time, 24% stated that it interferes with patient care, 20% stated that staff was not consulted, and 16% stated that patients cannot give informed consent (Kirsh et al.). These statements give researchers direction on how to improve the survey tool and on how to improve the introduction and timing of the survey to the hospice staff in order to improve the acceptance and cooperation of the staff.

The fore mentioned studies clearly show the importance of being sensitive to the unique emotional needs of the end of life patient and family in order to minimize the risk of emotional harm but that evaluating the effectiveness of end of life care is ethically appropriate and
necessary. In fact, Bruera (1994, p.9) concludes that, “one of the major ethical issues we must confront during the coming decade is whether we can afford not to make a major commitment to research in palliative care”.

*Validity*

All research studies should use valid and reliable instruments. Instruments are valid when they study what they intended to study. A study must be reviewed and well founded in order state that it is a valid study. It is interesting to note that the literature suggested that most tools used in the study of end of life care are not valid (Avis, Bond, & Arthur, 1995; Leimkuhler & Muller, 1996). There may not be congruence with expressions of satisfaction and experience of satisfaction due to fulfillment of expectations. This relationship is sometimes wrongly assumed when using non-validated instruments for research. Research suggests that to fully understand this relationship, researchers have to understand the mechanisms underlying the expressions of satisfaction (Williams et al., 1998). This may be achieved by having a reviewed and valid instrument, i.e., questionnaire. The study conducted by Williams et al. took 15 subjects and interviewed them individually in two parts: (1) unstructured discussion of the patient’s experience of the services they received (2) structured discussion based on the patient’s answers to a satisfaction questionnaire. This study introduced the idea of “duty” and “culpability” to describe how a positive or negative experience turns into a positive or negative description of service. “Duty” is defined to be the patient’s perception of what they believe the services should and should not do and what the roles and obligations of a service are to the user. Duty can then be related to the patient’s feelings on how the service is working for them and if it is working correctly. “Culpability” is defined as whether or not the service is to be blamed if it does things
that it shouldn’t or fails to do things that it should. Most people will not respond negatively towards lack of “culpability” or “duty” if it is due to failure, instead, they will make excuses for why the particular circumstance did not allow the service to be performed as it should. The study showed that many patients’ experiences did not correlate with their satisfaction of the services provided for them. They may have a negative experience but report the experience as positive due to the failure of “culpability” or “duty” because of a certain circumstance. Therefore, “duty” and “culpability” must be taken into account when a researcher wants to correlate experiences with evaluations. In order to fully understand the satisfaction of the participant the researcher must assess the experiences of services and the value attached to determine whether the patient is truly satisfied with services provided (Williams et al.).
Some reasons that questionnaire instruments fail validity testing are non-congruence of questions, biased questions, exhaustive questionnaires, and small sample size. Questionnaires that have been poorly constructed are a major problem to validity. They may give misleading results, not allow patients to fully express their feeling of un-satisfaction, and suggest to researchers and clinicians that the patients are satisfied when they definitely are not (Whitfield & Baker, 1992). Measures need to be taken in the design of the questionnaire in order to achieve a valid instrument.

Fig. 1. Tree diagram showing process links between experiences and expressions of dis/satisfaction.
In order to provide evidence that is valid and reliable the instrument must be valid and reliable (Walsh & Walsh, 1998). Validity consists of two principle types: Measurement or test validity and design or experiment validity. Measurement or test validity poses the question of whether the measure actually does what it is intended. Face, construct, and concurrent validity are subsets of measurement or test validity and are ways a questionnaire may be deemed a valid instrument. Face validity asks whether the particular method appears to be appropriate. This validity is the weakest form of validity and relies on expert opinion to determine whether or not face validity is present (Blessing, 2005). Researchers in the area of palliative care may want to discuss their survey with physicians that are experts in palliative care, palliative care nurses and social workers in order to confirm face validity. Construct validity asks whether the measurement is based on theory (Blessing). In the realm of satisfaction surveys, the theory is that the questionnaire given to the patient and/or caregiver will demonstrate satisfaction with services provided as long as “duty” and “culpability” are taking into account. Concurrent validity asks whether the test performs as well as an accepted test (Blessing). Researchers can confirm concurrent validity by comparing their study with the study of other researchers working to prove the same idea. Literature reviews and analysis of final statistics taken from the survey will be able to prove or disprove concurrent validity. Design or experiment validity is formed on the ideas of internal and external validity. Internal validity is concerned with limiting or controlling factors and events, other than the independent variable, which may cause changes in the outcome (i.e. dependent variable) (Blessing). In studies about palliative care at the end of life researchers must take into account attrition from death, as this is a huge reality in this population and is a threat to internal validity. External validity is concerned with factors which may affect the generalization of the conclusions drawn from a study (Blessing). Accessibility is
a threat to external validity in the palliative care setting because patients may be too weak or not have the cognitive capacity to complete the survey being distributed. By asking this series of questions and working to minimize the threats to validity as well as studying other instruments that have been used previously to assess congruency, we can determine validity of the study. Ensuring instrument validity allows the findings to be applied to the clinical arena and also provides a basis for further research.

Appropriate statistical tests are another way to prove validity of an instrument and should be applied to all research. Sulmasy et al. (2002) conducted a study in which they distributed the Quality of End-of-Life care and Satisfaction with Treatment scale (QUEST) to 257 in-patients at two different teaching hospitals. The purpose of the study was to validate and ensure reliability of the QUEST scale. They were able to assess construct validity and test-retest reliability by performing the study on a smaller sample of patients at another hospital and by using the appropriate statistical measures to ensure their assessment. The study was able to show a high reliability due to a Cronbach alpha score of 0.83 to 0.95 for the four QUEST scales. Cronbach alpha helps to show how well items measure a single uni-dimensional latent construct, meaning that the findings were consistent with each other. A Cronbach alpha of 0.70 or higher is considered acceptable in most social science research (http://www.ats.ucla.edu/stat/Spss/faq/alpha.html). This study is a good resource for researchers seeking to validate and ensure reliability of their study.

Reliability

Instruments are reliable when they give the same results in successive trials. Accuracy and reliability are often confused in the literature and researchers must understand the difference
between the two. Reliability deals with consistency in which a measurement is taken, it does not deal with how close it is to the intended outcome. Accuracy deals with how close the results are with the intended outcome of the study. A study can be reliable but not accurate. Instrument reliability needs to be conducted in order to ensure study reliability. To determine an instrument’s reliability is to determine consistency of the instrument. The statistical test to determine reliability on nominal levels of measurement (naming, classification) and ordinal levels of measurement (categories plus magnitude; aka Likert scale surveys) is the Kappa or weighted Kappa. Kappa is a measure of agreement between data. Complete agreement corresponds with a K=1 and lack of agreement, meaning random coincidences, corresponds with a K=0. The Pearson correlation coefficient is described in articles also, but this statistical test is inappropriate to assess reliability because it is vulnerable to systematic error. Researchers must strive to perform the correct statistical test so they can come to correct conclusions about data being analyzed.

Survey Questions

As previously mentioned the questions asked in the questionnaire are a major point in determining whether the researcher will see the correct results and if those results are correlated to the questions asked. If questions are asked in the wrong way the study will not provide useful information, no matter how well other aspects of the design are implemented (Peterson, 2000). Validation of the survey will be in jeopardy if the questions are worded improperly or are interpreted improperly by the participants.

Researchers must know how to properly construct a survey if it is to be used as a valid study. Effective questionnaires should be formulated as though they are within normal
conversation and should obey standard grammatical rules and regulations. Common sense is also used in effective questionnaires, but researchers need to identify what is common sense to the sample included in the study, and tailor the survey to them. Knowledge of the participants must also be calculated when constructing a survey so that the survey is not beyond what the participant can understand and interpret. Another way to develop effective questionnaires is to have experience in this area of study. Researchers who have constructed many questionnaires may be better able to discern acceptable questions from non-acceptable questions. Peterson developed criteria to be used with effective questionnaires and they are as follows: be brief, be relevant, be unambiguous, be specific, and be objective (Peterson, 2000). Being brief refers to being simple in the questions asked; lengthy questions can make a participant confused and exhausted due to the time constraints of deciphering what the question is actually asking. Being relevant refers to the question dealing with the specific research being conducted. If a participant deems the question not relevant, they will be more likely not to respond and thus will decrease sample size and possibly validity. Being unambiguous refers to wording questions in the simplest and least confusing terms possible. The researcher should not use words that can have double meanings, are unfamiliar, or can be interpreted differently in certain situations. Being specific refers to the questions that may have two sides to an answer. If the question mentions two different ideas in the one sentence, the answers given must have all possibilities to both ideas. However, a researcher needs to be aware as to not make the question so specific that the participant is unable to completely answer the said question (Peterson). Being objective refers to the question being un-bias; this is a necessity for any validated and reliable survey. Surveys for research purposes must allow the patients to develop their own opinion and answers to the specific question, there should not be any leading questions suggesting the participant to pick a
particular answer. When taking all these criteria and guidelines into account, a researcher can be assured that the questionnaire is valid and the participants will be able to respond without bias or confusion.

Fowler describes that one principle of ensuring an effective survey is to consider the format in order to make reading, following instructions, and recording answers easy (Fowler, 1995). Participants completing the survey may not be very motivated or have other means of not properly analyzing the questions; so the survey must be considered easy to read, easy to follow, and easy to answer. Peterson touched on how to make a questionnaire easy to read, but in order for a survey to be considered easy to follow it should have clear distinctions of instructions by use of capital letters or bolded letters, it should also be consistent in margins and spacing between questions, boxes can be utilized to highlight certain words or questions that are important, and above all make it obvious to the participant how to answer the questions by giving them clear instructions. Following these guidelines will ensure an increase of responses by participants.

Reasons to re-conduct a study

Steele et al. conducted their study using 321 patients and 443 caregivers, who completed surveys, over a two year time period. The subjects and their caregivers were enrolled in a hospice program during the time of survey completion. The study was in a setting of home care hospice in the southeastern United States of America which provided a full range of services to support patients and their caregivers (Steele et al., 2002). Two Likert scale instruments were used to assess satisfaction among the participants: (1) a 14 item patient satisfaction survey, and (2) a 14 item caregiver satisfaction survey. The Likert scale consisted of answers ranging from
very satisfied, satisfied, somewhat satisfied, somewhat dissatisfied, and not applicable on the patient satisfaction survey. This did not allow the patients to express their neutrality or complete dissatisfaction with the service being asked by the question. How are the researchers supposed to assess satisfaction and dissatisfaction when the patients are not able to answer without bias?

The Likert scale for the caregiver satisfaction survey consisted of answers ranging from very satisfied, satisfied, neutral, dissatisfied, to very dissatisfied. The questions addressed satisfaction with various aspects of hospice care including: staff, communication, education, promptness of service, symptom management, plan of care, family support, and overall satisfaction with care.

The questionnaire for the patients was mailed at 60 days of care, and there was a telephone follow-up call after the questionnaire was sent to remind the subject to complete and return the survey (Steele et al., 2002). This survey had an alpha reliability coefficient of 0.84. This is not the correct coefficient to assess reliability on an ordinal scale of answers. As fore mentioned, the Kappa statistical analysis is the correct test to assess a Likert scale which is considered ordinal level data. The caregiver satisfaction survey was mailed one month after the death or discharge of the patient and this survey had an alpha reliability coefficient of 0.77. Again, the alpha reliability coefficient should not be used and the Kappa coefficient should be used to assess ordinal data. Another consideration in the distribution of the survey was there may have been a “halo effect” when mailing the surveys to the caregivers one month after their loved ones had passed away. The caregivers may be grateful for everything hospice had done for them and their loved ones and they could just be relieved that their loved one is no longer suffering. If they were to mail the surveys while the patients were in active hospice care the caregivers may be more apt to express their concern and dissatisfaction with hospice.
In this particular study they assigned numbers to corresponding answers to evaluate the Likert scale and determine their conclusions. This allowed the researchers to conduct a series of analytical tests on the results of the surveys. The researchers conducted tests dealing with means and standard deviations. However, with ordinal level data, means and standard deviations cannot be used accurately. The statistics should be non-parametric statistics which allow the analysis of categorical data. Therefore, this study, concluding satisfaction of both patients and their caregivers, cannot be considered valid since the wrong statistical tests were performed to evaluate and analyze the responses to the survey questions. However, this study did include the comments that patients and caregivers noted on their respective surveys which showed a positive attitude toward hospice and their services. Also, in the discussion portion of the study the researchers did recognized that a valid and reliable instrument needs to be developed in order to increase the effectiveness of the study. Their preliminary data suggests that hospice is a program that decreases pain and suffering for patients at the end of life which allows the patient to die peacefully in their homes (Steele et al., 2002).

Summary

Hospice and hospice home care is becoming a increasingly large industry due to the baby boomers aging and due to more people becoming aware of the various ways in which hospice can aide both the patient and their caregiver. In order to ensure that hospice is providing their patients the best possible care, evaluation research must be conducted in this area of medicine. Evidence based medicine is the cornerstone of practice and hospice should be no different. In order to accurately evaluate the services of hospice, patients and caregivers should be able to express their satisfaction with their experiences through questionnaires. Plus, the only way that
questionnaires can be evaluated accurately is if they are created correctly without bias, are stated simply, have non-ambiguous questions, and contain pertinent questions. They also must be analyzed statistically with the correct tests in order to be considered valid and reliable. Researchers can then confidently conduct a study in the palliative care area.

Research in this area must keep the patient and their unique situation in mind at all times. The IRB and experts in the palliative care realm should work in conjunction with each other in order to monitor the research being conducted. When researchers perform their studies in the ways suggested, they will be able to ensure that their research is ethical and non-harmful to the patients and their caregivers.
Methods

This study uses survey methodology, with data being gathered through paper and pencil technique. Approval for this study was obtained through the University of Toledo Biomedical IRB prior to data collection.

Problem Statement

Hospice care is a growing industry around the world. The success of hospice care and services should be evaluated by assessing the satisfaction of hospice patients and their caregivers. Evaluation is best conducted through questionnaire methods to minimize risks to the patients and risks to the caregivers. In order to trust the results of an evaluation process and to confidently apply the findings to patient care, the evaluation instrument must be validated and reliable. For an instrument to be valid means the instrument is appropriate for the results being sought and to be effective. For an instrument to be reliable means the instrument is able to give the same results on successive trials. The purpose of this research project is to revise, validate, and repeat a previously completed satisfaction survey of hospice patients and their caregivers.

Participants

The sample includes hospice patients involved with Blanchard Valley Bridge Home Health and Hospice. It includes patients from the three branches of this hospice: Bowling Green, Findlay, and Tiffin. In total, 84 patients were identified to be under Bridge Home Health and Hospice care. Of those 84, 26 were described by their home care nurse to be Alert and Oriented x 3. Caregivers were identified as the person who provides direct care to the respective 26
patients in their homes. Exclusion criteria for this study are the following: (1) patients under the age of 18 and (2) patients who have any cognitive impairment.

Patient Questionnaire

This survey was based on another survey study that was completed by Steele et. al. in 2002. In the first part of the survey, patients were asked about their age, race, and gender.

The second part of the survey asked the patients to select from a list of services they have received while in hospice home care. The services included: Nurse, Private duty, Social work, Volunteers, Hospice Care Center, Nurse Aide, Physical Therapy, Massage Therapy, Dietician, Chaplain, and other therapy(ies).

The third part of the survey asked a series of 11 questions about various aspects of hospice and the care they have been receiving. This part encompasses areas of timely services, admission to hospice, staff changes, knowledge of staff, treatment by staff, identification of staff, development of plan of care, instructions of treatment, office staff courteousness, night and weekend services, and equipment provided by hospice. At the end of this part of the survey there are a series of questions allowing the patient to express how well their concerns are being addressed about: pain, nausea, shortness of breath, bowel and bladder problems, agitation, family support, and other. This part also asks the patient about their overall satisfaction with hospice home care from Bridge Home Health and Hospice. All of these questions are based on a Likert scale ranging from: very satisfied, satisfied, somewhat satisfied, somewhat dissatisfied, dissatisfied, very dissatisfied, and not applicable.

The last part of the survey allows the hospice patient to write any additional comments that were not addressed by the survey or if they had any clarification of answers.
Caregiver Questionnaire

This survey was also based on the previous survey study completed by Steele et. al. in 2002. The first part of the survey asks the caregivers demographic information such as: age, race, gender, and relationship to the patient.

The second part of the survey asks various questions about the services and satisfaction with different aspects of hospice home care. The same Likert type scale was used for these questions include the caregiver’s subjective feelings about: education and training, their patients pain and symptom control, management of stress and anxiety, quality of life for their loved one, spiritual concerns, evening and weekend services, referral to Hospice, and satisfaction with Hospice assistance with hospitalization. “Yes” or “No” response questions were also asked in this section and pertained to: advanced directives, keeping their loved one from being hospitalized, if their loved one was hospitalized, and if they would recommend hospice to others.

The last part of the survey allows the caregiver to list ways that Bridge Home Health and Hospice could be improved and any additional comments they have concerning the survey or their answers to they survey questions.

Protocol

The one page questionnaire was mailed out to the previously identified patients and their caregivers in January 2009 through the Bridge Home Health and Hospice service in order to maintain confidentiality of the patients and caregivers. Participants were informed by an enclosed cover letter that the survey was to be anonymous and were asked not to place any identifiers on the envelope or the survey. There were identifying numbers placed on the corner
of the survey in order to differentiate patient surveys from the caregiver surveys. Participants were also informed that their completion of the survey implied informed consent to the study. It was identified that the only risk to the patient and caregiver was the 5-10 minutes that it would take to complete the survey and place it into the returned self addressed stamped envelope and that the participant would not be receiving any compensation for their participation.

If the participant agreed to be a part of the study, they were to complete the survey and mail it back in the self addressed stamped envelope provided for them in the original envelope. The questionnaire was asked to be mailed to Linda Miller, RN, BSN, MPH, via the stamped return envelope by February 2, 2009. The short time period was chosen to encourage the participants to respond sooner and hopefully prevent the participant from forgetting about the survey.

**Statistical Analysis**

Data from both surveys were coded and analyzed with Microsoft Excel and Statistical Product and Service Solution (SPSS) software. Descriptive analysis was obtained by using the frequency tables in the analysis section of the SPSS software. This was used to determine the number and percentage of respondents in each demographic group. Crosstabs were also run on the data to show the number and percentage of the participants and how they answered each question on the survey. Tables and figures of this data were configured using the SPSS software.
Results

*Caregiver Satisfaction Survey*

There were a total of 15 respondents who completed this survey. Demographic profiles of these respondents can be seen in Table 1 and Figure 1. The ages of participants ranged from ages 42 years old up to 84 years old. There was a noteworthy difference in the race/ethnicity of the caregivers with 93.3% Caucasian respondents and 6.7% Hispanic respondents. The amount of female caregivers far outweighed male caregivers with 66.7% female and 33.3% male. There were also a wide range of relationships of the caregiver to the patient, with the most common finding of 60% being spouses, 20% being other relatives, 13.3% being the patient’s own children, and 6.7% being a friend of the patient.

Table 2 displays responses to the nominal level data for the caregiver survey. It reveals that 93.3% of caregivers believe that hospice kept their loved ones out of the hospital and 93.3% of caregivers believed they received adequate information from hospice about advanced directives and the living will. The largest reveal from the data is that, 100% of caregivers would recommend hospice to others.

Table 3 displays responses to the ordinal level data for the caregiver survey. It reveals that 100% of caregivers responded with Very Satisfied to Somewhat Satisfied for the level of education that hospice gave them on admission. It also reveals 100% of caregivers responded with Very Satisfied to Somewhat Satisfied for the amount of pain control hospice was giving their loved ones. It showed that 100% of caregivers responded with Very Satisfied to Satisfied on the control that hospice had over the other symptoms their loved ones were experiencing. However, 6.7% of caregivers responded with Somewhat Dissatisfied with hospice efforts to help manage their stress and anxiety during their loved one’s hospice course; the other 93.3% of
caregivers responded with Very Satisfied to Somewhat Satisfied. A total of 80% of caregivers were either Very Satisfied or Satisfied with the amount of spiritual guidance from hospice and the other 20% responded to this question as non-applicable. A slightly lower number of 73.3% of caregivers responded as being Very Satisfied to Somewhat Satisfied with the amount of help from weekend or after-hours staff and the other 26.7% responded as being non-applicable. Of the caregivers who responded, 93.3% reported being Very Satisfied or Satisfied with the timeliness of referral to hospice and 6.7% reported this question being non-applicable. Lastly, 28.6% of caregivers were either Very Satisfied or Satisfied with the amount of assistance hospice provided in any hospitalizations of their loved ones and 71.4% reported this being non-applicable.

Table 4 shows responses to various questions that the caregivers were encouraged to write in their own responses or discuss why they responded the way they chose.

Patient Satisfaction Survey

There were a total of 14 patients who completed the satisfaction survey. Demographic profiles of these patients can be found in Table 5. Patients who responded varied in age with the youngest being 36 years old and the oldest being 89 years old. Again there was an ethnic bias with 92.9% of patients were of Caucasian race and the remaining 7.1% did not respond to this demographic question. Of those patients who responded, 42.9% were male and 50% were female.

Table 6 displays responses to the nominal level data on the Patient’s questionnaire. Surprisingly this showed that 100% of patients do not use the Physical Therapy, dietician, or other unnamed services that hospice offers to them. Patients did respond with 78.6% using the
home nursing services and 21.4% do not use home nursing services. Patients that use and don’t use the chaplain and social work services are split down the middle 50/50. A total of 35.7% of patients do take advantage of the volunteer services offered by hospice, but 64.3% do not. A small majority of patients use nursing aide services with 57.1% using and 42.9% not using them. Massage therapy offered by hospice only sees 14.3% of the patients surveyed. Also, private duty services only see 7.1% of these patients that responded.

Table 7 displays responses to ordinal level data on the Patient’s questionnaire. This reveals that 100% of hospice patients responded with Very Satisfied or Satisfied with their first hospice contact and admission process, with the knowledge of the staff, with the level of respect the staff shows them, with services provided within 30 minutes of quoted time, with agreeability of the plan of care established, with instructions about care and/or treatments, with courteousness of staff members, with timeliness to delivery and instructions for use of equipment, and with control of pain. In regards to the minimum amount of staff changes the patients have to endure, 100% responded anywhere from Very Satisfied to Somewhat Satisfied. Of those surveyed, 83.3% of patients were Very Satisfied to Satisfied with the promptness of after hour and weekend services, with the other 16.7% of patients responding to this being Non-Applicable. In respect to control of their agitation, 44.4% of patients were Very Satisfied, 44.4% of patients were Satisfied, and 11.1% of patients responded Non-Applicable. However, 9.1% of patients were Somewhat Dissatisfied with the amount of family support offered by hospice with the other 90.9% being Very Satisfied or Satisfied. Of those patients who responded to their concerns being addressed about their shortness of breath, 63.6% were Very Satisfied, 27.3% were Satisfied, and 9.1% were Non-Applicable. Lastly of those patients who responded about their
concerns of nausea, 38.5% were Very Satisfied, 38.5% were Satisfied, and 23.1% responded as Non-Applicable.

Table 8 displays responses to a comment section that the patients were encouraged to write in what they would like.
Discussion

As all clinicians know, the baby boomers are growing older and the elderly population is living longer. This population presents with an increase in more chronic disease states and cancers. Hospice is a program set up for the terminally ill to assist in end of life care for patients and transition for families and caregivers. This study was based on the Steele, et al study in 2002 which provided beginning data about measuring patient and caregivers’ satisfaction with hospice care in many different aspects. Our study further describes the satisfaction of caregivers and their loved ones and adds validity to the Steele study. Overall, our study has shown that there is a 100% satisfaction rate with hospice home care patients and a 100% satisfaction rate with caregivers for these patients who would recommend hospice to others in need of help.

Hospice makes many services available to the caregivers as well as the patients and 93.3% of caregivers surveyed believed that hospice educated them well on the amount and availability of these services. As opposed to the (Steele et al., 2002) study where they had a percentage of 99.5% who believed they had adequate explanation. However both studies demonstrated a 93% satisfaction of adequate information about advanced directives to the caregivers. The Steele et al. study demonstrated a 99.5% of caregivers stating they did receive a clear explanation of the hospice services and how to access them as opposed to the current study which demonstrated a 93.3% satisfaction rate of explanation of services. The final item for Nominal data considers if hospice kept the caregiver’s loved one from being hospitalized. Steele et al. concluded that 94.7% of caregivers agreed to this statement as opposed to the current study’s conclusion of 100% of caregiver agreement.

Unfortunately the current study cannot compare with the Steele et al. study on any ordinal level data due to the former study incorrectly analyzing this type of data.
The current study was able to demonstrate overall satisfaction with hospice as a whole and with hospice as individual parts. There are aspects of which hospice can work to improve as in working with caregivers to reduce their stress levels and working with families of hospice patients to ensure their support during this difficult time in all their lives. Hospice can also work on keeping their staff paired up with the same patients to reduce change for the patient and families and in turn reduce stress levels. Also, as demonstrated in the questionnaire, there are many services that hospice makes available that is not being used by the home care hospice patient population. Hospice can use this study as a guide to what services can be promoted more and utilized more often.

In terms of validating a study, the current study was able to perform as predicted. The study was able to complete an un-bias questionnaire for patients and caregivers and statistically identify and analyze data correctly. This can be used as a template for other studies to be based upon because validation is a sought after reference when completing studies.

**Limitations**

The current study has several limitations. The study population and response rate was very low. In order to receive a higher validation and power percentage, there should be a larger study conducted. One way to increase validation and the response rate would be to include more than one hospice service, in more than one city, in a certain state. We can not conclude that all patients and their caregivers are satisfied with hospice care due to the low response rate. There is the possibility that those who were not satisfied, did not wish to participate in research about hospice. Another limitation is this study is that only home care patients and their caregivers were included. There is another population of hospice patients that are in an inpatient hospice
facility receiving care. We cannot assume or conclude that these patients share in the home care patients’ satisfaction of hospice since they were not studied. A further limitation for the population sampled was the homogeneity of race in patients and caregivers with 93.3% of caregivers being Caucasian and 100% of patients being Caucasian. This can become more heterogeneous if the study is expanded to include different cities and different hospice facilities.

Strengths

Strengths of this study include the 50.9% response rate of patients and caregivers. A usual survey strives to receive around the 20% response rate. The study set a small time frame to receive surveys back so the participants did not wait to complete the surveys and then ultimately forget. The home care nurses and staff did an excellent job to make known the survey and encouraged the patients and their caregivers to participate in order to help hospice serve them to the best of their ability. Another strength is the further validation and reliability this placed on the Steele et al., 2002 study that was previously conducted. This study identified the statistical errors that were made during the aforementioned study and corrected them using the SPSS system. Ultimately descriptive studies were only able to be ran on this data because the surveys were much different from each other. This study allows another researcher to follow our methods, adapt them to a wider hospice population, and ensure validation and reliability.
Conclusion

With the backbone of medicine being in evidence based practice and the increasing number of elderly patients as well as terminally ill patients, hospice needs to be a program that can be studied and concluded to be a sound medical institution. In order for practitioners to feel comfortable admitting patients to hospice, reliable and validated satisfaction survey should be completed. This survey has identified areas that can be improved in the hospice realm and identified areas that are of excellent quality as well.

Satisfaction surveys completed by patients and caregivers serve as a means to evaluate hospice and the services they offer. This should be a continuous effort to keep patients and caregivers confident in the care that hospice offers as well as content with treatment of their loved ones and family. Satisfactions surveys must be valid and reliable in order to be used in the medical field. All hospice facilities should choose a survey that is non-biased, as well as easy to read for their patients and caregivers. The risk to the participants is minimal if the survey is not invasive and does not consist of language they cannot comprehend. Reading level should be kept to a 5th grade level to ensure no confusion. Surveys are the most beneficial when comparing the differences between caregiver and patient satisfaction if they are identical surveys and with cross tabs made between the surveys; however, this may not always be feasible due to the different services provided to each population.

In conclusion, hospice continues to be a service that is well received by home care patients and caregivers alike. In order for hospice to ensure continued reliable service, they must conduct a regimen of valid and reliable satisfaction surveys to their patients and caregivers. Results should be analyzed and care plans should be adjusted appropriately to reflect the needs of the patient and care given. Hospice, like other medical providers, need to conduct studies to
ensure they are practicing evidence-based medicine. With continued efforts of hospice centers around the world and up to date satisfaction studies, they will be able to ensure continued satisfaction of their patients and caregivers.
References


[http://www.ats.ucla.edu/stat/Spss/faq/alpha.html](http://www.ats.ucla.edu/stat/Spss/faq/alpha.html)
Table 1  
*Characteristics of Caregiver Survey Respondents:*

<table>
<thead>
<tr>
<th>Demographic Information</th>
<th>Percentage (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>93.4%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6.7%</td>
</tr>
<tr>
<td>Male</td>
<td>33.3%</td>
</tr>
<tr>
<td>Female</td>
<td>66.7%</td>
</tr>
<tr>
<td>Spouse</td>
<td>60%</td>
</tr>
<tr>
<td>Other Relative</td>
<td>20%</td>
</tr>
<tr>
<td>Child</td>
<td>13.3%</td>
</tr>
<tr>
<td>Friend</td>
<td>6.7%</td>
</tr>
</tbody>
</table>
Figure 1
*Relationship of Caregivers to the Patients*
Table 2
*Caregiver Satisfaction Survey Responses to Nominal Level Data:*

<table>
<thead>
<tr>
<th>Question</th>
<th>%Yes</th>
<th>%No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clear explanation of services</td>
<td>93.3</td>
<td>6.7</td>
</tr>
<tr>
<td>Adequate information about advanced directives</td>
<td>93.3</td>
<td>6.7</td>
</tr>
<tr>
<td>Kept from being hospitalized</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Hospitalized under hospice care</td>
<td>21.4</td>
<td>78.6</td>
</tr>
<tr>
<td>Recommend hospice</td>
<td>100</td>
<td>0</td>
</tr>
</tbody>
</table>
Table 3  
*Caregiver Survey Responses to Ordinal Level Data:*

<table>
<thead>
<tr>
<th>Question</th>
<th>%VS</th>
<th>%S</th>
<th>%SS</th>
<th>%SD</th>
<th>%D</th>
<th>%VD</th>
<th>%NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>60</td>
<td>33.3</td>
<td>6.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Pain</td>
<td>73.3</td>
<td>20</td>
<td>6.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Symptoms</td>
<td>53.3</td>
<td>46.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Stress</td>
<td>53.3</td>
<td>26.7</td>
<td>13.3</td>
<td>6.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>QOL</td>
<td>66.7</td>
<td>26.7</td>
<td>6.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Spiritual</td>
<td>46.7</td>
<td>33.3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>After hour</td>
<td>40</td>
<td>26.7</td>
<td>6.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>26.7</td>
</tr>
<tr>
<td>Referral</td>
<td>60</td>
<td>33.3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6.7</td>
</tr>
<tr>
<td>Hospital</td>
<td>21.4</td>
<td>7.1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>71.4</td>
</tr>
</tbody>
</table>

Key:
- VS= Very Satisfied
- S= Satisfied
- SS= Somewhat Satisfied
- SD= Somewhat Dissatisfied
- D= Dissatisfied
- VD= Very Dissatisfied
- NA= Non Applicable

- Education= How satisfied are you with the education and training you received after admission to hospice?
- Pain= How satisfied are you with the control of the patient’s pain control after admission to hospice?
- Symptoms= How satisfied are you with the control of the patient’s other symptoms after admission to hospice?
- Stress= How satisfied are you with hospice efforts to help you manage your stress and anxiety during the illness of your loved one?
- QOL= How satisfied are you with the hospice efforts to support your loved one’s quality of life?
- Spiritual= How satisfied are you with hospice efforts to assist you with spiritual concerns?
- After hour= If you contacted the evening or weekend on-call service, how satisfied were you with the response?
- Referral= Were you satisfied that your loved one was referred to hospice at the appropriate time during the course of the terminal illness?
- Hospital= If applicable, how satisfied are you with hospice assistance with any hospitalization?
### Table 4
Caregiver’s Candid Responses to Open Ended Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>“Response”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on the care your family receives, would you recommend hospice to</td>
<td>Yes, no other service provides the quality of care, concern, and dedication demonstrated.</td>
</tr>
<tr>
<td>others?</td>
<td>Yes, hospice is a wonderful service to allow loved ones to be home.</td>
</tr>
<tr>
<td></td>
<td>Yes, I know of many families that have had help with hospice care, everyone has been totally appreciative and satisfied.</td>
</tr>
<tr>
<td></td>
<td>Yes, they are very supportive.</td>
</tr>
<tr>
<td></td>
<td>Yes, they have been excellent and kept our dad from going to a rest home.</td>
</tr>
<tr>
<td></td>
<td>Yes, based on the care given, I would gladly recommend hospice!</td>
</tr>
<tr>
<td></td>
<td>Yes, everyone is so nice, like family.</td>
</tr>
<tr>
<td></td>
<td>Yes, all of the nurses are very caring.</td>
</tr>
<tr>
<td></td>
<td>Yes, they are here to help you with any problem and to keep their patient very comfortable.</td>
</tr>
<tr>
<td>Please list ways that hospice services could be improved.</td>
<td>Aids need better training</td>
</tr>
<tr>
<td></td>
<td>By each and every hospice employee we’ve encountered so far. I hesitate to get very satisfied with anything only because satisfaction can lead to complacency on my part. As far as improvements, I feel that hospice is fine the way it is, don’t change it!</td>
</tr>
<tr>
<td></td>
<td>Hire weekend only nurses. Don’t like having our regular during week nurse because she has been on call on weekends.</td>
</tr>
<tr>
<td>Additional comments:</td>
<td>The hospice staff is extraordinary. They make a point to go out of their way to fulfill any needs of the patient or our family. They make an excellent effort to include our daughter and help us help her through this rough time. Hospice is a wonderful resource for anyone facing a terminal illness.</td>
</tr>
<tr>
<td>We feel blessed to have such wonderful people willing to come anytime to give us assistance. My sister has been doing so much better under hospice care. Thank you!</td>
<td></td>
</tr>
<tr>
<td>We (I) am so happy with everyone involved with hospice. Thanks, thanks, thanks! Has made my life easier!</td>
<td></td>
</tr>
<tr>
<td>God Bless you all</td>
<td></td>
</tr>
<tr>
<td>We appreciate so much the faithfulness of the nurses who visit twice a week. Also, the quick response when we lost electricity during a bad storm. They took care of my husband and moved him into a hospital. Praise the Lord!</td>
<td></td>
</tr>
<tr>
<td>Wonderful people, hope to volunteer myself someday.</td>
<td></td>
</tr>
</tbody>
</table>
Table 5
*Characteristics of Patient Survey Respondents:*

<table>
<thead>
<tr>
<th>Demographic Information</th>
<th>Percentage (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>92.9%</td>
</tr>
<tr>
<td>Missing Race</td>
<td>7.1%</td>
</tr>
<tr>
<td>Male</td>
<td>42.9%</td>
</tr>
<tr>
<td>Female</td>
<td>50%</td>
</tr>
<tr>
<td>Missing Gender</td>
<td>7.1%</td>
</tr>
</tbody>
</table>
Table 6  
*Patient Survey Responses to Nominal Level Data:*

<table>
<thead>
<tr>
<th>Services Used</th>
<th>% Yes</th>
<th>% No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Therapy</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Dietician</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Nurse</td>
<td>78.6</td>
<td>21.4</td>
</tr>
<tr>
<td>Social Work</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Volunteers</td>
<td>35.7</td>
<td>64.3</td>
</tr>
<tr>
<td>Nurse Aide</td>
<td>57.1</td>
<td>42.9</td>
</tr>
<tr>
<td>Massage Therapy</td>
<td>14.3</td>
<td>85.7</td>
</tr>
<tr>
<td>Chaplain</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Hospice Care Center</td>
<td>28.6</td>
<td>71.4</td>
</tr>
<tr>
<td>Private Duty</td>
<td>7.1</td>
<td>92.9</td>
</tr>
</tbody>
</table>
Table 7
Patient Survey Responses to Ordinal Level Data:

<table>
<thead>
<tr>
<th>Question</th>
<th>%VS</th>
<th>%S</th>
<th>%SS</th>
<th>%SD</th>
<th>%D</th>
<th>%VD</th>
<th>%NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admission</td>
<td>92.3</td>
<td>7.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Timeliness</td>
<td>76.9</td>
<td>23.1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Changes</td>
<td>53.8</td>
<td>30.8</td>
<td>15.4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Knowledge</td>
<td>84.6</td>
<td>15.4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Respect</td>
<td>92.3</td>
<td>7.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Identify</td>
<td>84.6</td>
<td>15.4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>POC</td>
<td>61.5</td>
<td>38.5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Instructions</td>
<td>92.3</td>
<td>7.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Staff</td>
<td>84.6</td>
<td>15.4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>After hour</td>
<td>50</td>
<td>33.3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>16.7</td>
</tr>
<tr>
<td>Equipment</td>
<td>90</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Pain</td>
<td>75</td>
<td>25</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>B/B</td>
<td>60</td>
<td>30</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Agitation</td>
<td>44.4</td>
<td>44.4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>11.1</td>
</tr>
<tr>
<td>Support</td>
<td>54.5</td>
<td>36.4</td>
<td>0</td>
<td>9.1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>SOB</td>
<td>63.6</td>
<td>27.3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9.1</td>
</tr>
<tr>
<td>Nausea</td>
<td>38.5</td>
<td>38.5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>23.1</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Key:
- VS= Very Satisfied
- S= Satisfied
- SS= Somewhat Satisfied
- SD= Somewhat Dissatisfied
- D= Dissatisfied
- VD= Very Dissatisfied
- NA= Non Applicable

- Admission= The first hospice contact and the admission process were handled in a timely manner.
- Timeliness= Staff came to provide services within 30 minutes of when I was told to expect them.
- Change= There have been minimum changes in the staff providing care to me.
- Knowledge= Staff is knowledgeable about the services they provide.
- Respect= I am treated with respect and courtesy by the staff.
- Identify= Hospice staff members identify themselves by stating their names and titles and wearing their nametags.
- POC= I understand and agree with the plan of care developed.
- Instructions= Instructions about care and/or treatments are clear and thorough.
- Staff= When I call the agency, office staff are courteous and direct my call directly.
- After hour= When calling after 5:00pm and/or weekends the nurse on-call responded promptly and provided services.
- Equipment= Equipment was delivered as expected, works as it should, and proper instructions were given.
- Pain= My concerns being addressed about pain.
- B/B= My concerns being addressed about bowel/bladder problems.
- Agitation= My concerns being addressed about agitation.
- Support= My concerns being addressed about family support.
- SOB= My concerns being addressed about shortness of breath.
- Nausea= My concerns being addressed about nausea.
- Satisfaction= Overall, my satisfaction with services from Hospice.
<table>
<thead>
<tr>
<th>Question</th>
<th>“Response”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other Comments</td>
<td>I have nothing to complain about.</td>
</tr>
<tr>
<td></td>
<td>Hospice services have gone far past my expectations. Everyone I have dealt with make my feel like I am the only person they have to work on. Thank you so very much.</td>
</tr>
<tr>
<td></td>
<td>Each person that comes treats me with the greatest respect. They are kind to me and listen when I ask questions.</td>
</tr>
<tr>
<td></td>
<td>They take good care of me.</td>
</tr>
<tr>
<td>Hospice has been wonderful</td>
<td>Our satisfaction with hospice cant be measured. I do not have a negative word to say about hospice.</td>
</tr>
<tr>
<td></td>
<td>They all do a great job. Just about anybody says they are good!</td>
</tr>
</tbody>
</table>
Appendix A: Copy of cover letter attached to caregiver survey

Dear Caregiver to a Bridge Home Health and Hospice home care patient:

We are conducting research at the University of Toledo Health Science Campus to find out about your satisfaction with your experience with Hospice. You were chosen to be in this study based upon the reason that you are a primary caregiver for a patient enrolled in Bridge Home Health Hospice home care. Results from this study will be used for research purposes only.

The enclosed 1 page survey will take 5-10 minutes of your time to complete. Your decision to complete the survey will provide valuable information that will be used as feedback to Hospice and to improve the care of Hospice.

Your participation in this study is voluntary and anonymous. Your reply will not be seen by anyone but the researchers performing the study. Please do not place your name or any other information to identify yourself. There is a small number on the survey and this is to show that you are a caregiver to a patient in Hospice home care; this will be a way to keep the surveys between you and your loved one separate. When you finish the survey you can place it in the self addressed, stamped envelope given to you and send it back. Once we receive your survey your number and responses will be placed in a master list and your survey will be stored in a locked cabinet. By choosing to complete and send back the survey you are implying consent. Please answer the questions to the best of your ability and if you do not want to answer a certain question, please leave that answer blank.

Please return the completed survey by Monday, February 2nd, in the self addressed stamped envelope given. If you have any questions or concerns about the survey or its contents, please contact Karen Doten at Karen.doten@utoledo.edu or Linda Miller, RN, BSN, MPH at Linda.miller3@utoledo.edu.

Thank you for your time and participation,

Sincerely,

Linda Miller, RN, BSN, MPH
Director Human Donation Science Program
College of Health Science and Human Services
Principle Investigator and Research Advisor

Karen Doten, ATC, PA-S2
Graduate Student
Department of Physician Assistant Studies
Appendix B: Copy of cover letter attached to patient survey

Dear Bridge Home Health and Hospice home care patient:

We are conducting research at the University of Toledo Health Science Campus to find out about your satisfaction with your experience with Hospice. You were chosen to be in this study based on your affiliation with Bridge Home Health Hospice and their home care treatments that you are receiving. Results from this study will be used for research purposes only.

The enclosed 1 page survey will take 5-10 minutes of your time to complete. Your decision to complete the survey will provide valuable information that will be used as feedback to Hospice and to improve the care of Hospice.

Your participation in this study is voluntary and anonymous. Your reply will not be seen by anyone but the researchers performing the study. Please do not place your name or any other information to identify yourself. There is a small number on the survey and this is to show that you are a patient in Hospice home care; this will be a way to keep the surveys between you and your caregiver separate. When you finish the survey you can place it in the self addressed, stamped envelope given to you and send it back. Once we receive your survey your number and responses will be placed in a master list and your survey will be stored in a locked cabinet. By choosing to complete and send back the survey you are implying consent. Please answer the questions to the best of your ability and if you do not want to answer a certain question, please leave that answer blank.

Please return the completed survey by Monday, February 2nd, in the self addressed stamped envelope given. If you have any questions or concerns about the survey or its contents, please contact Karen Doten at Karen.doten@utoledo.edu or Linda Miller, RN, BSN, MPH at Linda.miller3@utoledo.edu.

Thank you for your time and participation,

Sincerely,

Linda Miller, RN, BSN, MPH
Director Human Donation Science Program
College of Health Science and Human Services
Principle Investigator and Research Advisor

Karen Doten, ATC, PA-S2
Graduate Student
Department of Physician Assistant Studies
Appendix C: Copy of survey sent to caregivers

Caregiver Satisfaction Survey

Demographic Information:

Age: ____________________ Race: __________________________ Gender: _______________________

Relationship to patient: __________________________________________

Please circle your response:

1. Were you given a clear explanation of what services were available through Hospice and how to access them?
   - Yes    
   - No

2. How satisfied are you with the education and training you received after admission to Hospice?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Dissatisfied
   - Very dissatisfied
   - Not applicable

3. How satisfied are you with the patient’s pain control after admission to Hospice?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Dissatisfied
   - Very dissatisfied
   - Not applicable

4. How satisfied are you with the control of the patient’s other symptoms after admission to Hospice?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Dissatisfied
   - Very dissatisfied
   - Not applicable

5. How satisfied are you with Hospice efforts to help you manage your stress and anxiety during the illness of your loved one?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Dissatisfied
   - Very dissatisfied
   - Not applicable

6. How satisfied are you with Hospice efforts to support your loved one’s quality of life?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Dissatisfied
   - Very dissatisfied
   - Not applicable

7. How satisfied are you with Hospice efforts to assist you with spiritual concerns?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Dissatisfied
   - Very dissatisfied
   - Not applicable

8. Did Bridge Home Health and Hospice provide you with adequate information about “advance directives” like the living will?
   - Yes    
   - No

9. If you contacted the evening or weekend on-call service, how satisfied were you with the response?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Dissatisfied
   - Very dissatisfied
   - Not applicable

10. Were you satisfied that your loved one was referred to Hospice at the appropriate time during the course of the terminal illness?
    - Very satisfied
    - Satisfied
    - Somewhat satisfied
    - Somewhat dissatisfied
    - Dissatisfied
    - Very dissatisfied
    - Not applicable

11. Do you think Hospice services helped keep your loved one from being hospitalized?
    - Yes    
    - No

12. Was the patient hospitalized while under Hospice care?
    - Yes    
    - No

13. If applicable, how satisfied are you with Hospice assistance with any hospitalization?
    - Very satisfied
    - Satisfied
    - Somewhat satisfied
    - Somewhat dissatisfied
    - Dissatisfied
    - Very dissatisfied
    - Not applicable

14. Based on the care your family receives, would you recommend Hospice to others?
    - Yes    
    - No
    - Why/Why not?

15. Please list ways that Hospice services could be improved:

   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
16. **Additional comments:**                                                                                                                    
                                                                                                                                             
Thank you
Appendix D: Copy of survey sent to patients

**Patient Satisfaction Survey**

**Demographic Information:**
Age:________________________ Race:________________________________ Gender:____________________

*Please select from the list of services all those you receive from our agency:*
Nurse  Social work  Volunteers  Nurse aide  Massage therapy  Chaplain  Private duty  Hospice care center  Physical therapy  Dietician  Other therapy

*Please circle your response:*

1. The first Hospice contact and the admission process were handled in a timely manner.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

2. Staff came to provide services within 30 minutes of when I was told to expect them.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

3. There have been minimum changes in the staff providing care to me.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

4. Staff is knowledgeable about the services they provide.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

5. I am treated with respect and courtesy by the staff.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

6. Hospice staff members identify themselves by stating their names and titles and wearing nametags.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

7. I understand and agree with the plan of care developed.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

8. Instructions about care and/or treatments are clear and thorough.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

9. When I call the agency, office staff are courteous and direct my call directly.
   Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

10. When calling after 5:00p.m. and/or weekends the nurse on-call responded promptly and provided services.
    Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

11. Equipment was delivered as expected, works as it should, and proper instructions for use were given.
    Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

12. My concerns are being addressed about:
    a. pain: Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable
    b. nausea: Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable
    c. short of breath: Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable
    d. bowel/bladder problems: Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable
    e. agitation: Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable
f. family support: Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

g. other (please specify): __________________________________________________________________________

14. Overall, my satisfaction with services from Hospice:
Very satisfied  Satisfied  Somewhat satisfied  Somewhat dissatisfied  Dissatisfied  Very dissatisfied  Not applicable

Other Comments:
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
_____________________________________________________________________________________

Thank You
Abstract

Objective: This study examined home care patient and their caregivers’ satisfaction with Bridge Home Health and Hospice.

Methods: A self-completed survey sent through U.S. postal service to patients’ homes and caregivers’ homes to assess satisfaction of various aspects of hospice services. Descriptive statistics were obtained.

Results: Overall, patients were 100% satisfied with hospice and the care received by them. Caregivers were 100% satisfied and would recommend hospice services to others. There are aspects of hospice care that could be utilized more by the patients and caregivers.

Conclusion: This survey further demonstrated the satisfaction of patients and caregivers for home care hospice. This survey also further validated and increased reliability of a previous study conducted. Hospice continues to be a facility where patients and caregivers believe they are being treated with respect and treated correctly medically.