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Quality of Life in the Hospice Patient

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QUALITY OF LIFE IN THE HOSPICE PATIENT

By

Sidney S. Brush

A THESIS

**Submitted to
Grand Valley State University
in partial fulfillment for the
degree of**

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1999

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ABSTRACT

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The purpose of this study was to determine if terminally ill patients experience a change in perceived quality of life between admission to a hospice program and after having been in the hospice program for three weeks.

A repeated measures design with a convenience sample was used. The sample consisted of 56 subjects who completed the Missoula-Vitas Quality of Life Index (MVQOLI). Twenty completed the second MVQOLI. Data were obtained from the scores of this self-assessment tool. Data analysis included a comparison of the relationship of the first and repeated scores. No significant differences were found between the MVQOLI scores from Time 1 to Time 2.

The individual dimensions of Quality of Life (Symptom, Functional, Interpersonal, Well-Being, and Transcendence) were analyzed using the paired T-test, Chi-square and the Wilcoxon matched-pairs test. A statistically significant improvement was demonstrated in the individual dimension of Transcendence.

**This research project is dedicated to all the Hospice Patients
I have had the privilege to meet and care for.
I thank them for all they have taught me
through their living and their dying.**

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CHAPTER ONE

INTRODUCTION

Quality of life is a dynamic concept and may change over the course of illness and treatment (Varricchio, 1990). The definition of quality of life (QOL) is subjective in nature as individuals have very personal definitions of their own concept of quality of life. People also differ in the importance they place on various aspects of illness, which causes a differential impact on the experience of life (Ferrell, 1990). Dramatically different responses about perceived QOL may be observed even in people with the same clinical condition (Guyatt, 1993). Therefore, measuring quality of life represents a challenge because cultural, ethnic, religious and other personal values determine how quality of life is judged (Ferrell, 1990). Until recently, QOL was typically measured by physical ability, improvement and rehabilitation. The focus now is more on the individual's experience rather than on the conditions of life (Ferrell, 1990).

The quest for QOL is especially prominent in palliative care when symptom control rather than curative intervention is of importance (Bullinger, 1992). The core of palliative care emphasizes concern for quality over quantity of life (Cella, 1992). Nurses are the primary health care providers for people with terminal illness and, as such, are invited into the most intimate, emotional aspects of their lives (Ferrell, 1993). Quality of life is an important concept for nurses who practice in oncology settings because they are faced with the physical, psychological, social, and spiritual needs of the patients who are

affected by the disease and its treatment.

Quality of life is increasingly recognized as a significant outcome measure for nursing interventions. Varricchio (1990) believes that the degree to which a person finds that life is worth living is an appropriate nursing care outcome. Measurement of QOL is important to health care providers and payors as a measure of success of programs and a demonstration of the merit of care. This outcome is of particular significance to hospice programs in their work with terminally ill patients. The domains of physical, psychological, social and spiritual are identified as aspects of QOL (Cohen, 1992). Hospice programs offer symptom relief along with psychosocial, financial, legal and spiritual support. Maximizing quality of life is actively fostered in the hospice program. Maintaining or improving perceptions of well-being is a priority for hospice patients.

Though many disciplines have struggled to define QOL, none have succeeded in doing so (Gill, 1994). Many existing studies focus on functional status and expectations of improvement with curative or life prolonging treatments. Most QOL scales for patients with cancer do not address social well being and lack questions about overall social level or family activity compared to their lives before having a cancer diagnosis (Cella, 1992). A review of the literature has found very few studies attempting to measuring QOL in the hospice patient (McMillian, 1996; McMillian & Mahon, 1994). To be effective, quality of life instruments should measure all attitudes of the mind, body and spirit (Donovan, Sanson-Fisher, and Redman, 1994). An instrument that could accurately measure quality of life in the terminally ill and dying patient, while minimizing the emphasis on the physical component, would be of great benefit to hospice programs.

Byock and Merriman (1996) developed the Missoula-Vista Quality of Life Index (MVQOLI) (Appendix A), a self assessment tool designed to measure the subjectively experienced quality of life of hospice patients. The MVQOLI is based on the research of developmental landmarks and tasks at the end of life (Byock, 1996). These landmarks and tasks include the sense of completion with worldly affairs, relationships with community, family and friends. Also included are having a sense of meaning about one's life and life in general, experienced love of self and others and finally an acceptance of the finality of life and surrender to the unknown. Attaining these landmarks and tasks are believed to help the person achieve an improved quality of life at the end of life with the capability to die well.

The MVQOLI was made available to hospice programs to assess QOL of their patient population. Implemented initially by researchers with patients admitted to a hospice program, as a one time measurement, the MVQOLI had not been used to determine if there is a difference in perceived QOL from the time a patient is admitted to a hospice program compared to a time period after being in the hospice program. Since one of the main goals of a hospice program is to maintain and/or improve quality of life of it's patients, an instrument such as the MVQOLI could be used to assess this outcome. In addition, the MVQOLI may identify ways to improve hospice programs that enhance quality of life.

Purpose

The purpose of this study was to determine if terminally ill patients experience a change in perceived quality of life between admission to a hospice program and after having been in the hospice program for three weeks.

CHAPTER TWO

REVIEW OF LITERATURE AND CONCEPTUAL FRAMEWORK

This chapter will cover five different areas. These will include (a) a definition of quality of life (QOL), (b) QOL studies in the terminally ill, cancer, and hospice patient, (c) the limitations of QOL research, (d) the conceptual framework for this study, and (e) conceptual and operational definitions.

Review of the Literature

Quality of Life

Quality of life is an individual's subjective perception of his/her well being, including all physical, emotional and spiritual aspects. Subjectivity refers to the idea that QOL can only be assessed from the individual's perception (Cella, 1992).

QOL and the Terminally Ill

AIDS patients frequently are defined as terminally ill, and may often be referred to hospice programs. Nickel, et.al. (1996) compared monthly QOL results of two different groups of AIDS patients using the Quality of Well-Being Index. One group was case managed (n=29) and the other (n=28) received usual care from agency home care nurses. The comparison results showed no statistical difference between the two groups and in both groups QOL results declined with time. Hospice patients were included in this study. However, since hospice patients were under represented, the findings cannot be generalized to this group of patients.

QOL and Cancer Patients

The relationship between age and physical and psychosocial quality of life in cancer patients was examined using a quality of life assessment tool. Mor (1992) analyzed data from three studies examining this relationship. The three samples included 698 aging patients in a medical treatment follow up program for two years after an initial cancer diagnosis, a group of 150 patients requiring short term nursing care after starting outpatient chemotherapy, and 372 patients in a multisite study evaluating home care needs of patients starting a course of chemotherapy or radiation therapy. Questions and scales measuring physical and psychosocial quality of life were used in all three studies. The aggregated findings suggested that age does not affect the cancer patients' perceived quality of life at the time of diagnosis or while undergoing treatment (Mor, 1992).

Zacharias, Gilg, and Foxall (1994) studied QOL and coping in 40 gynecology cancer patients and also in their spouses. A cancer version QOL scale was used to compare the responses of the patients and of their spouses. No significant differences were found between patients and their spouses in overall QOL. Both groups identified 'family' as the most important QOL indicator.

Ferrans (1994) used a QOL measurement to study 61 breast cancer survivors, of whom 67% had at least a 5 year survival. Despite the fact all subjects had cancer, most of these patients could not be considered terminally ill, since some had the diagnosis of cancer for 10 to 28 years. The majority of the survivors were characterized as 'getting on with living'. They apparently had put their cancer behind them and it no longer negatively influenced their QOL. In another study, Ferrell (1995) examined quality of life in 687 long term cancer survivors, the mean age was 49.6 and 81% were female.

This study identified factors indicative of improved QOL, which included positive aspects of hopefulness, purpose in life and improvement in relationships. Patients with improved QOL had feelings of usefulness, happiness, and satisfaction. More research is needed to determine if these positive characteristics can be identified among the terminally ill population in general.

Glimelius, Hoffman, Graf, Pahman, and Sjoden (1994) studied QOL in patients undergoing palliative chemotherapy treatment for colorectal cancer. Subjects were at least 75 years old and had incurable symptomatic colon cancer. Their QOL for cancer survivors instrument, which included FACT- G (Functional Assessment of Cancer Therapy-General), was randomly given to 70 patients and repeated after the fourth course of treatment. The measurement used an interview (24 patients) and a questionnaire (46 patients) which asked about troublesome events, pain, symptoms, and psychosocial concerns. The study showed an overall improvement in QOL in 25 patients (36%). Sixteen patients had no change in their perceived quality of life during at least a four month period. The study suggested QOL was improved more in those patients with fewer symptoms.

Strengths and Limitations of QOL Research in the Terminally Ill

Besides functional capability, these studies examined many dimensions of life. The perception of less tangible aspects such as hopefulness, purpose in life and importance of relationships were identified. This suggests that researchers are beginning to include aspects other than physical ones when studying quality of life.

Few studies have attempted to measure the QOL of the patient in a hospice program. Research on QOL, the chronically ill, and the cancer patient does not

necessarily generalize to the hospice patient. These patient groups have a different focus on life. Unlike the hospice patient, they are not usually facing their final stage of life. Studies of patients' perception of QOL and their cancer treatment program or of cancer survivors have little in common with the hospice patient whose life expectancy is predicted to be less than 6 months.

Many of the studies reviewed had small samples. It is often difficult to perform repeated testing. This may be due to the fact that initial and follow up test responses are greatly affected by mortality and attrition. The willingness of subjects to report more than once and the time factor with terminal illness often affect the data collection return rate.

Research suggests that patient self reporting is preferable compared to reporting by primary caregivers. Caregivers have the tendency to report a higher QOL for the patient than the patient reports (McMillian and Mahon, 1994).

QOL and Hospice Patients

Historically, QOL of the patient in a hospice program has not been studied. Recently, two researchers (McMillian, 1996, McMillian and Mahon, 1994) have published studies regarding QOL and the hospice patient. McMillian (1996) used a convenience sample of 118 patients newly admitted to a hospice care program. The patients and their primary caregivers were given a tool to assess the perception of the patient's quality of life at the beginning of care and again after three weeks. All the subjects had cancer, were predominately Caucasian, with study participants equally male and female. All lived in private homes, most were Protestant, with the next largest belief Catholic, and only six reported no religious affiliation. Seventy four of these patients

survived the three weeks and, of these, 62 were able to complete the second index.

Quality of life remained stable with the supportive care from the hospice program. Although some patients indicated an improved quality of life nearer death, the difference between the initial survey and three weeks later was not significant. Interestingly, the primary caregivers reported perceiving a significant improvement in the patients' quality of life during this time. The correlation between patients' and caregivers' perceptions of the patients' QOL was moderate at admission and week four ($r = .55$, $p < 0.01$ and $r = .51$, $p < 0.01$, respectively). This study concluded that quality of life assessments were more accurate when based on patient generated data, rather than on family or caregiver interpretation. Earlier studies have indicated quality of life diminishes closer to death, whereas, the results of McMillian's study indicate stability in quality of life over the period of the study.

McMillian and Mahon (1994) reported that 50% of the patients surviving 6 weeks in a hospice care program had improved quality of life. Quality of life was measured on each patient who completed a 25 item analogue scale upon admission to the hospice program and again three weeks later. Each patient served as his own control and 31 of the original 67 survived to complete the second index. None of the findings were statistically significant. However, the results did suggest that hospice care may have a positive influence on some aspects of quality of life for some patients who are near death. The responses did show a limited improvement in pain after three weeks, identifying an important area to concentrate on for future hospice interventions.

In this study, 80% had the diagnosis of cancer and there were more male (64.6%) than female participants. The researchers suggest future studies control for diagnosis and

include the number of days before death. The vast majority of patients' quality of life declines rapidly at the very end of life and if it does remain stable, this may suggest improvement over what was anticipated (McMillian & Mahon, 1994). An index utilizing this type of measurement could support the positive effects of a hospice program.

Hospice philosophy includes maintaining and/or improving QOL. These studies attempt to document QOL in the hospice patient and validate the merit of the hospice program. The nature of terminal illness and dying may account for the lower return rate of the second questionnaire. Even though subjects' responses did not demonstrate a significantly improved QOL, physically declining and close to death, their responses may substantiate a better QOL than would be expected. The study suggests that patient self reporting is more accurate than QOL assessed by family or caregiver.

Conceptual Framework

Imogene King's conceptual framework was used in this study. Imogene King (1981, p.10) developed an open systems conceptual framework, consisting of three dynamic and interacting systems: personal, interpersonal, and social. All of these systems are in continuous exchange with their environment (George, 1989) and when these are in equilibrium, health is obtained. The environment is described as being both internal and external. The internal environment involves the biological and psychological make-up of the person and in the hospice patient this may be described by their illness, symptoms and spiritual issues. The external environment is the physical and social milieu, which would comprise the patients' medications, palliative chemotherapy, and/or radiation therapy, along with their functional ability, social support and financial

concerns. The hospice patient would be unlikely to have the equilibrium that would equate to perceived health. King (1981, p.5) defines health as "dynamic life experiences of a human being, which implies continuous adjustments to stressors in the internal and external environment through optimal use of one's resources to achieve maximum potential for living". Although the stressors are increased and the objective potential for daily living is decreased, if the hospice patient has the assistance needed, he/she might face their stressors and maximize their daily activities, thereby maximizing their QOL and achieving a greater degree of "health" while approaching death.

From the perception of King's conceptual framework, the personal system is the patient with a terminal illness, who interacts in the interpersonal system, the hospice program and team members. The social system is comprised of the patient's family, friends, physician, and societal influences, including one's roles in their family and community. Perception is the main concept of the personal system. King defines perception as "a process of organizing, interpreting, and transforming information from sensory data and memory... a process of human transactions with environment. It gives meaning to one's experience, represents one's image of reality and influences one's behavior" (King, 1981, p.24). Perception is the way a person sees or interprets a situation. The person's perception, understanding and interpretation of reality influences all behaviors in a unique manner, which varies from individual to individual. Perception is action oriented in the present and based on available information. It is not possible to make assumptions about another persons' QOL; it is only their own perception of their quality of life that matters (Sutcliffe and Holmes, 1991). The best way to know what a person feels about their quality of life is to ask them (Towlson and Rubens, 1992).

The interpersonal system of King's conceptual framework, is formed by human beings' interactions. The main concept of the interpersonal system is the exchange of information through body language and manner of speech. It is the observable behavior of two or more people interacting with one another. Communication is the "process whereby information is given from one person to another, either directly or indirectly" (King, 1981, p.79). Communication occurs when the sender accurately conveys the message to the receiver to achieve a mutual understanding. Both the sender and the receiver should check the accuracy of the other's understanding of the message. If communication between the hospice team and the patient consists of congruent perceptions and mutual role expectations, the transaction will occur. "If transactions are made in nurse-client interactions, growth and development will be enhanced" (King, 1981, p. 149).

King's theory of goal attainment supports communication and transactions to achieve mutual goal setting. With mutual goal setting the client and the nurse participate together in decisions regarding the plan of care. Mutual goal setting can have a major influence on the effectiveness of nursing care, since the client is an active decision maker. The philosophy of hospice supports the client being the decision maker, with the hospice nurse and team providing the necessary information to make informed decisions.

The hospice team engages in transactions to achieve mutual goal setting between staff and client and encourages transactions with the patient and their family. Therefore, the expectation is that being in the hospice program would increase or at least maintain quality of life.

Objective of the Study

The objective of this study was to identify any change in the perceived quality of life of terminally ill patients between admission to a hospice program and after being in the program at least 3 weeks.

Conceptual and Operational Definitions

To facilitate examination of QOL among the terminally ill, the following conceptual and operational definitions are offered:

Hospice program. Hospice is a program and philosophy designed to support terminally ill patients and their families through the patients' final months of life and expected death. It is the intent of hospice programs to aid patients in the attainment of the best quality of life for the duration of their lives. Hospice uses a multidisciplinary team approach consisting of registered nurses, medical social workers, home health aides, ministers, medical doctors and trained volunteers. The team provides nursing care, personal care, emotional counseling, interventions for symptoms control, and assistance for the patient and family during stressful periods.

A Midwest hospice program was used in this study. Members of this hospice team visited the patient regularly at their residence. Patients were usually cared for in their home by a family member or friend. Patients may be residents of nursing homes or other facilities such as adult care or group homes and still be enrolled in the hospice program.

Each patient was assigned his or her own primary nurse and social worker. The primary nurse visited the patient in his or her home as indicated by their needs and clinical condition, usually averaging two to three times a week. The social worker

addressed emotional, financial and practical concerns and visited upon admission and one to two times a month or as determined by the situation. The home health aides attended to personal care on a daily basis as needed. The pastoral staff made at least one contact after admission and then as requested, irrespective of religious preference. Pastoral staff visits were frequently in addition to the patient's and family's own minister. The medical directors were consultants to the attending physicians and the primary nurses and made home visits as requested. Trained volunteers were available once a week to assist the patient and family in the home and /or run errands as requested.

Patient. All the hospice patients had a terminal disease with no known cure nor were they seeking an active cure. Their life expectancy was usually predicted to be six months or fewer.

Quality of life. Quality of life as defined by Byock and Merriman (1997, p.7) is "the subjective assessment by an individual of his or her experience of well being".

Research question

What difference was there between patients' perceived quality of life upon admission to a hospice program and that measured three weeks later?

CHAPTER THREE

METHODS

This study evaluated terminally ill patients' perceived quality of life upon admission to a hospice program compared to three weeks later (as measured by the Missoula-Vitas Quality of Life Index (MVQOLI)). This chapter will discuss (a) the research design, (b) subjects and their demographic characteristics, (c) the MVQOLI and scoring, (d) procedure for data collection, (e) protection of human rights, and (f) instrumentation.

Research Design

The research design used in this study was a repeated measures design. The data for this study was collected at a Midwestern hospice. The subjects who agreed to participate in the study completed the MVQOLI upon admission and again in three weeks, if able. Data were collected until a convenience sample of 56 subjects completed the first index with 20 of these subjects repeating the second index.

Subjects

Subjects were excluded if they could not read English, were excessively debilitated (physically or mentally incompetent), confused, disoriented, or in a coma or semi-coma. The nurse admitting the client to the hospice determined any excluding factors. Sex or age (above 18 years old) were not excluding factors. Subjects receiving palliative treatment (chemotherapy or radiation) may be enrolled in the hospice

program and, therefore, were eligible to participate in the study.

Characteristics of the Subjects

There were fifty-six subjects that completed the initial MVQOLI after admission to the hospice program. Of the participants twenty seven (48.2%) were male and 28 were female. The age of the participants ranged from 37 to 86; the average age was 71 years (SD 11.39). The majority of the participants were Caucasian (94.6%), married (64.3%) and had at least a high school education (85.7%). Only one participant resided in a long-term facility while the remaining participants lived in a private home with their spouse (53.6%), children (17.9%), other family members (7.1%), or friends (3.6%).

Missoula-Vitas Quality of Life Index (MVOOLI) Instrument

Permission (Appendix B) was obtained to use the MVQOLI assessment tool for the subjects in this study. It is composed of 25 items and has an estimated 10-20 minute completion time. Some items are statements with which the participant agrees or disagrees by placing a mark in one of five circles arranged linearly between these two end points. Some items have two opposing statements to denote the extremes of a subjective response. The answers were transposed to a numerical value for scoring.

The MVQOLI was constructed to include five dimensions in evaluating the terminal and dying patient. These dimensions of symptoms, functional status, interpersonal relationships, emotional well-being and transcendence are based on the patient's perception of quality of life.

The symptom dimension refers to the person's experience of physical discomfort associated with progressive illness and the resulting level of physical distress. The functional dimension is the perceived ability to perform accustomed functions and the

activities of daily life experienced in relation to the person's expectations and their associated emotional response. Interpersonal aspects reflect the degree of investment in personal relationships and perceived quality of one's relationships with family and friends. The self-assessment of an individual's internal condition includes the feeling of well-being, the subjective sense of wellness or disease, and contentment or lack of contentment. Transcendence is the experienced degree of connection with an enduring construct, the degree of experienced meaning and purpose of one's life (Byock, 1994).

Scoring. A unique system, a Weighted Dimension Score, was developed for this index (Appendix C). Each of the five dimensions is scored in relation to one of the categories of assessment, satisfaction and importance. The assessment is a subjective measurement of actual status or circumstance, for example, of how the patient feels. Satisfaction reflects the emotions or feelings in response to their actual circumstances. The importance factor is the degree to which a given dimension has an impact on their quality of life. Within each of the five dimensions, the scores of the assessment and satisfaction items are added, the sum divided by two and then multiplied by the numerical importance value assigned by the patient to create a Weighted Dimension Score (Byock, 1996). Possible scores range from -30 to + 30, indicating the range of the most negative to most positive responses. The scoring algorithm for the MVQOLI is somewhat arbitrary. Total scores are calculated by summing the weighted dimensional subscores and converting the result to a positive score between 0 and 30. The total score reflects a multidimensional quality of life weighted according to the individuals' identification of their most important dimensions (Byock & Merriman, 1998).

Psychometric properties. The MVQOLI was administered by its originators to over 300 hospice patients in ten different centers. Results indicated it exhibited reliability and content validity with a population of terminally ill patients receiving hospice care. Reliability was measured by calculating Cronbach's alpha coefficient for internal consistency, which was stable at 0.77 (Byock & Merriman, 1997). The reliability coefficients for the five individual dimensions were not reported.

Reliability was also demonstrated by the comparison of the mean total scores for each participating research site to the overall mean total score; scores were consistent from site to site. Content validity was analyzed based on the review of the instrument by hospice professionals and patients. The acceptability of the instrument for over 85% of participants at various educational levels indicated that the MVQOLI was relevant and sensible to participants.

The overall reliability analysis in this study was 0.78. The dimension reliability coefficients calculated for the individual dimensions were lower than the total reliability and are presented in TABLE 1.

Table 1

Dimension Reliability Coefficients

Dimension	Coefficient
Overall	.78
Symptom	.29
Function	.57
Well-being	.58
Interpersonal	.68
Transcendence	.55

Procedure

The hospice registered nurse presented and explained (Appendix D) the MVQOLI to each new patient upon admission to the hospice program and offered them an opportunity to participate in the study. If the patient agreed, an informed consent (Appendix E) was obtained at that time. The MVQOLI was left with the subject with a request to complete it within one week. The primary nurse delivered the second MVQOLI to the patient three weeks after completion of the first index. Patients were given an addressed stamped envelope with each MVQOLI to enable its return to hospice when completed.

Human Subject Considerations

Authorization was granted by the Executive Director of this hospice program to utilize and analyze all completed MVQOLI collected from patients admitted to this hospice program (Appendix F). The MVQOLI was already being distributed to new clients by this hospice agency. The primary investigator was employed by this hospice and had the responsibility for assessing the quality of service. Approval was also obtained from the Human Subjects Review Committee at Grand Valley State University (Appendix G).

There was minimal risk to the subjects in this study, aside from the possibility that the time taken to complete the questions may have tired the patient and confronting the concept of death in some of the statements may have disturbed some patients. The hospice team specializes in helping the patient and family confront impending end of life. The social worker was contacted to visit the subject if they were troubled by facing any of the statements addressed in the study. The actual occurrence of this was being

reported was rare, however, the MVQOLI did provide an important and meaningful starting point of conversation and communication between the subject and the hospice staff. All subjects were assured of confidentiality. Subjects were coded only by number and were not identified by name on the returned indexes. Returned numbered indexes were kept confidential and entered into the data base system.

Validity Issues with Design

Internal validity may have been threatened by the testing itself. The pretest might have influenced the responses on the posttest; however, an interval of three weeks was selected to decrease the likelihood that the subject would remember their initial responses to the statements. In this longitudinal study, there were missing data due to patients becoming too ill or dying before completing the second survey. The primary nurse re-evaluated the patient before distributing the second index to ensure that he/she could mentally and/or physically be retested. A convenience sample drawn from a single hospice limits the generalizability of this study.

CHAPTER FOUR

DATA ANALYSIS

The purpose of this study was to identify changes, patterns or trends in perceived quality of life (QOL) over time among patients enrolled in a hospice program. The research question posed for this study was "what change is there in the patient's perceived quality of life between admission to a hospice program and after three weeks of hospice care?" Data analysis was accomplished by using the Statistical Package for Social Sciences (SPSS\WIN) software.

Hypothesis

The hypothesis of this study was: Terminally ill patients experience a change in perceived quality of life after being in the hospice program for at least three weeks. Statistical analyses used in this study were paired t-tests, Chi square and Wilcoxon matched-pairs test. A level of significance at $p < .05$ was established for all statistical procedures.

Subjects

There were fifty-six subjects that completed the initial MVQOLI. Twenty of the these (36%) completed two MVQOLI, one upon admission and then again after at least three weeks in the hospice program. The other 36 subjects did not return the second MVQOLI due to various reasons; 27 died, one declined, one was hospitalized and then died, two moved out of the hospice district, and four did not respond for unknown

reasons.

Descriptive statistics were used to analyze the general characteristics and demographic data of the participants. Demographic characteristics were compared to determine if those who completed the MVQOLI at both intervals were different from those who completed the MVQOLI only one time. There were no significant differences based on gender, age, race, marital status, educational level, living arrangements, reported religious affiliation, diagnosis or perception of overall health and quality of life in the two groups.

The participants were asked about their perception of their overall health status. Fifty one (92.7%) of the subjects reported they perceived their overall health status as good. Several terminal diseases were represented, along with varying lengths of time of being aware of the diagnosis. Health related data are presented in TABLE 2.

Table 2

Health Related Data

Subjects	Number	Percent
Diagnosis (n=56)		
Cancer	47	83.9
End Stage Heart Disease	4	7.1
End Stage Lung Disease	1	1.8
ALS	1	1.8
Renal Failure	1	1.8
Cirrhosis	1	1.8
Unknown	1	1.8
Length of time aware of terminal diagnosis (n=56)		
< 1 month	17	30.4
1 - 3 months	11	19.6
4 - 6 months	11	19.6
7 - 12 months	4	7.1
> 12 months	13	23.2

In this study, of the 20 participants who completed MVQOLI both times, 13 (65%) were female and 7 (35%) were male. Their ages ranged from 37 to 86 years, the mean age was 70.4 (SD 14.10) and the median age 76.5. The majority (95%) of the participants were Caucasian and 95% had been married, or were divorced or widowed. Seventeen of the twenty subjects (85%) perceived a good overall adult health status until their current diagnosis. The remaining characteristics are presented in TABLE 3.

There was, however, a difference in the lengths of stay in the two groups. The average length of stay for the 36 subjects who did not complete the second survey was 45 days, the range was from 6 days to 90 days. Twenty seven (75%) of these 36 were in the hospice program 45 or fewer days. The average length of stay in the hospice program for the 20 participating subjects who completed both MVQOLI was 142 days or 4.5 months. The length of time they were in the hospice program ranged from 40 days to 317 days.

Table 3
Subject Demographics

Subject	Number	Percent
Religion (n=20)		
Catholic	3	15
Protestant	13	65
Other	1	5
None	2	10
Unknown	1	5
Living Arrangements (n=20)		
Private Home	14	70
With: Spouse Only	10	50
Children Only	4	20
Family	2	10
Educational Level (n=20)		
Grade School	3	15
High School	9	45
Associate Degree	1	5
Bachelor Degree	3	15
Graduate Degree	4	20

Table 3 (continued)
Subject Demographics

Subject	Number	Percent
Diagnosis (n=20)		
Cancer	18	90
End stage Heart Disease	2	10
Length of time aware of terminal diagnosis (n=20)		
< 1 month	7	35
1 -3 months	4	20
4 - 6 months	1	5
7 - 12 months	1	5
> 12 months	7	35

Quality of Life Results

The MVQOLI Weighted Dimension Scores results may range from -30 to + 30. The more or less positive or negative the number indicates the degree of importance in that dimension. The range of actual responses on the initial MVQOLI was from -27.5 in the functional dimension, the worst score, to +30 in all of the dimensions. In the repeat MVQOLI the worst score was again in the functional dimension (-30.00) to positive scores of +30.00 in the interpersonal, well-being and transcendence dimensions. The functional mean score dropped the lowest from time 1 to time 2 while the transcendence mean score stayed the highest. It would be expected that the terminally ill patient would experience functional decline close to death, while still being able to improve their perceived spirituality. The total score measuring individual's perceived multidimensional quality of life remained the same with a mean of 20.78 in time 1 and 19.32 in time 2.

A paired t-test was used to identify changes in perceived QOL in the MVQOLI global score from time 1 to time 2. The quality of life global score results may range from +1 to +5. Both global 1 and global 2 mean scores were almost identical. Time 1

was 3.80 and time 2 was 3.90 ($p = .59$). Thus, there was not a significant difference in the global score in the subjects responses from time 1 to time 2.

A paired t-test was also used to identify any change in each of the five dimensions: symptoms, functional status, interpersonal relationships, emotional well-being and transcendence from time 1 to time 2. TABLES 4 and 5 show the actual responders score ranges, mean, and SD in each of the five dimensions and the global quality of life score for the subjects at time 1 and time 2.

Table 4
Participants MVOOLI Scores at Time 1 (n=20)

Dimension (5 items each)	Range	Mean	SD
Symptom	- 4.00 to +30.00	7.26	6.58
Function	-27.50 to +30.00	7.21	16.25
Interpersonal	- 4.00 to +30.00	17.53	9.99
Well-Being	-10.00 to +30.00	9.10	11.21
Transcendent	- 7.50 to +30.00	12.84	10.89
Total Score	+17.25 to +25.25	20.78	2.42
Global Score	+ 2.00 to + 5.00	3.80	1.05

Table 5
Participants MVOOLI Scores at Time 2 (n=20)

Dimension (5 items each)	Range	Mean	SD
Symptom	-7.50 to +16.50	6.00	4.99
Function	-30.00 to +25.00	2.02	14.71
Interpersonal	-3.00 to +30.00	18.60	10.88
Well-Being	-10.00 to +30.00	8.59	9.02
Transcendent	-7.50 to +30.00	19.52	10.88
Total Score	+13.90 to +23.00	19.32	2.54
Global Score	+1.00 to +5.00	3.90	1.29

Using rank ordering, the relationship of all the 25 MVQOLI questions were analyzed with the Wilcoxon Matched-Pairs Signed-Ranks Test, from time 1 to time 2. For the majority of the questions, there was no significant change noted. Review of the data indicated some subjects changed in their perception of quality of life on individual answers. Three of the questions had a statistically significant change (Table 6) and four questions had a close relationship (Table 7). Eleven out of 20 subjects responded more negatively regarding their independence with ADL (activities of daily living) and their ability to do things over time. The other five questions were positively more significant. These questions pertained to the person's feelings of closeness to others, their sense of connection, the meaning of life, their comfort with the thoughts of death and having their affairs in order.

Table 6

Comparison of questions statistically significant from time 1 to time 2 (n=20)

Question	Deviations from T1 - T2
#7 Ability to do things	p = .01 10 out of 20 responded more negatively
#12 Closeness to others	p = .02 9 out of 20 responded more positively
# 22 Sense of meaning in life	p = .02 10 out of 20 responded more positively

While not statistically significant, participants responded more positively in areas of their affairs being in order, their sense of connection and being comfortable with the thought of death. As would be expected, the majority of those responding had less independence with their daily activities.

Table 7

Comparison of questions with a close relationship from time 1 to time 2 (n=20)

Question	Deviations from T1 - T2
#6 Independence with ADL	p = .09 11 out of 20 responded more negatively
#16 Affairs are in order	p = .09 5 out of 20 responded more positively
# 21 Sense of connection	p = .09 7 out of 20 responded more positively
#23 Comfort with thought of death	p = .059 8 out of 19 responded more positively

The five dimensions of function, symptoms, well-being, interpersonal and transcendence were looked at individually for any significant change from time 1 to time 2. In four of the dimensions, there was no significant change (Table 8).

However, in the transcendence dimension, a significant improvement ($p = .01$) was demonstrated. Transcendence indicates the degree of meaning and purpose of one's life. The overall philosophy of hospice and the team members conveying this concept to the hospice patient by their interventions, support, listening and caring for the patients' physical, spiritual and emotional concerns may have positively influenced the transcendence dimension.

Table 8

Hypothesis (n=20)

Dimension	Mean time 1	Mean time 2	t	p
Symptom	7.26	6.00	.73	.47
Function	7.21	2.02	1.07	.29
Interpersonal	17.53	18.60	-.29	.77
Well-Being	9.10	8.59	-.33	.74
Transcendent	12.84	19.52	2.83	.01
Total Score	19.87	20.46	-.86	.40

The paired t-tests were used to analyze the differences in the total and dimension scores for the subjects completing the MVQOLI at both time 1 and time 2. The total mean scores were 19.87 for time 1 and 20.46 for time 2. Only the dimension of transcendence showed a significant difference between times 1 and 2 (paired $t=2.83$, $p=.01$). There was no significant difference between time 1 and time 2 for the 20 subjects in the global score for the subjects' perceived quality of life ($p=.58$). As previously suggested, no change may imply improvement over anticipated decline. However, the research hypothesis was not supported in this study.

CHAPTER FIVE

DISCUSSION AND IMPLICATIONS

The findings of this study did not support the hypothesis that the perceived overall quality of life of the hospice patient changes from admission to a hospice program compared to after being in the program for three weeks or longer. In general, the hospice subjects who participated in the study indicated similar perceived quality of life on both Missoula-Vitas Quality of Life Index (MVQOLI) returned at different time intervals. There were, however, a few exceptions.

Palliative care in the hospice setting focuses on relief of symptoms and improvement or maintenance of quality of life. Five different quality of life dimensions were measured within the MVQOLI, including symptoms, functional, interpersonal, well-being and transcendence. The transcendence dimension demonstrated a statistically significant improvement from the initial MVQOLI results compared to results after the subject had been in the hospice program three weeks or longer. Transcendence may be the most powerful way to restore wholeness when facing a life defining illness. It refers to the experienced meaning and purpose of one's life. This is the spiritual meaning of one's life and exists apart from the material universe. This improvement suggests that the important aspects and values of the subjects' lives were being positively addressed and may be reflective of the holistic philosophy presented in hospice care.

The other QOL dimensions did not demonstrate a significant change. The

symptom dimension may be expected to improve at times in the first three weeks of hospice care because of the medical and nursing interventions to help the patient achieve better pain and symptom control. However, many terminal patients may experience different and worse symptoms nearer death. The function dimension could be anticipated to decline, as it is expected for the terminally ill patient to decline physically and perhaps mentally as they get closer to death. Hospice care may not be expected to make a difference in the symptom and functional dimensions when death is near. It may be an advantage to document the time interval between completing the MVQOLI and the time of death, and evaluate any changes in comparison with this time frame.

The interpersonal dimension measuring ones' perceived quality of relationships may be influenced by the transcendence score. Family is frequently identified as an important factor for the patient at the end of life. The dimension of well-being, the subjective sense of wellness, may rely more on hopefulness and relationships than do the physical dimensions. A very ill person could possess a high degree of personal well being.

The majority of the participants in the present study were terminal with a cancer diagnosis and lived in a private home with family members. Of the 56 subjects, only 52% survived the time period and 36% of the 56 subjects were able to complete the second questionnaire. There was a very high mortality rate in these subjects. Almost half of the subjects did not survive three weeks in the hospice program and many of those who did, declined rapidly, making it difficult, and in some cases impossible, to complete the second index. Due to this attrition, it was difficult to obtain a higher number of subjects who completed both indexes.

An individual's perceived QOL may vary as symptoms and coping responses change as death comes closer. It may change from day to day as the perception of reality and health status change. As terminally ill patients' physical and emotional status change, so may the perceptions of their QOL.

The expectation was that being in the hospice program would improve or at least maintain perceived quality of life. This study indicates that perceived quality of life was maintained. Through accurate assessment, the hospice team can incorporate interventions to maximize the individual's perceived quality of life. The MVQOLI may be a tool that could help provide objective documentation for hospice intervention outcomes.

Relationship To Previous Research

The present study lends support to the similarities of previous research related to the perceived quality of life of the hospice patient. McMillian (1996) and McMillian and Mahon (1994) have indicated a similar pattern in reported perceived quality of life. Although perceived quality of life did not significantly improve over time, a level of quality was maintained, even as the hospice patient neared death.

Other studies have indicated that quality of life declines as the patient nears death. In a 1986 study, Morris et.al. showed a rapid decline in QOL scores in the last few weeks of life. The fact that reported perceived quality of life was maintained in this study may indicate an improvement over what was anticipated.

In addition, other studies did not indicate that they subdivided quality of life into several dimensions. Thus, it is unknown if the transcendence dimension would have demonstrated a significant improvement as an individual component of quality of life

measurement.

Relationship of Findings to the Conceptual Framework

According to this research, the hospice patients' perceived quality of life did not change significantly from admission to after being in the program for at least three weeks. Perception is the main concept of King's personal system (King, 1981, p.24) and is defined as the way a person interprets their own situation. Thus, it is not possible to make assumptions about another person's quality of life. Asking the individual, as was done in this study with the MVQOLI, is the best way to know how a person feels. The hospice patient is not likely to have the equilibrium described by King to achieve health in this conceptual framework. They may experience some stability with the interactions and support offered by being in the hospice program. This may help them face their stressors and maximize their quality of life while approaching death. The hospice patient and the staff come together to achieve transactions. This can lead to attainment of end of life goals through congruent perceptions and mutual goal setting.

Limitations and Recommendations

The findings of this research study are from a small, nonrandom sample (n=20) in one hospice program. Therefore, the findings cannot be generalized beyond the present sample. Generalizability could be facilitated by using random sampling and a larger sample from multiple hospice programs.

The fact that the majority of the subjects in this study were Caucasian was another limitation. Further research is indicated to determine the influence of other races and cultures on perceived QOL as the end of life approaches.

Another limitation may be that patients may be admitted to the hospice program

when their life expectancy is six months or less. The point in a patient's life where they have only six months to live may be difficult to estimate. Many physicians may be reluctant to make this determination in the belief that referring their patient to hospice may make the patient feel as if the physicians are giving up on them. Patients themselves may be hesitant in their acceptance of or consent to hospice care. For these reasons, admissions to this hospice have been closer to the end of life than desired by the providers of hospice care. Many of these patients declined quickly and thus were not able to complete the second index, as they were too close to death. Late admissions and short lengths of stay in the hospice program contributed to the paucity of data collected at time two.

The time interval of data collection and the time until death could also influence the research findings. A three week interval between the two administrations of the MVQOLI was chosen based on other studies and also the average length of stay in this hospice program. If there is a change to be noted in the perceived quality of life, that change may occur over a greater period of time. Monitoring at intervals, such as surveying every 30 to 60 days, may identify more variables in perceived quality of life of longer term hospice patients, especially in the individual QOL dimensions.

Other reasons for not being able to document a significant change in the perceived quality of life may be that the instrument is not sensitive enough to assess the subtle changes in the way the subject perceives quality of life. Polit and Hungler (1991) set acceptable reliability coefficients at $>.70$. The overall reliability coefficients of the MVQOLI instrument was acceptable at $.77$, however the individual dimension coefficients were between $.29$ and $.68$. These results may be due to both the small sample

size and the small number of items in each subscale. In addition, this is a new instrument and may need further testing and refinement.

Implications for Nursing

Nursing administrators could validate their hospice program's effectiveness with a reliable outcome measurement. Using a quality of life index could help document this outcome. It is the nursing administrator's responsibility to provide objective evidence of hospice interventions and outcomes to third party payors for their hospice program. A tool measuring perceived QOL would be important in determining an efficacious protocol and plan of care.

Nursing staff development programs for hospice nurses should focus attention on what each patient perceives to be important. In addition to the knowledge necessary for pain management and symptom control, the hospice nurse needs to be educated in understanding the end of life tasks and goals that need to be met to assist the dying patient to die well.

Nursing interventions should be based on the individuals' perceptions of what is important for their quality of life. By using a tool as the MVQOLI, the nurse could have measurable data on which to base, evaluate and revise individual patient interventions.

It is important to note that the purpose of this study was to identify any changes over time in the perceived quality of life of the hospice patient. It was not the objective of this study to identify interventions to help improve patients' perceptions of their quality of life. Further research is warranted in this area.

Suggestions for Future Research

Quality of life measurements for patients at the end of life could assist in directing the plan of care. By giving attention to maximizing QOL with dying patients, the opportunity to die well would be ensured. Language and culturally specific measurements might enhance the validity and reliability of the tool with minority populations. QOL instruments must be sensitive enough to detect change over time in an individual patient to determine and interpret clinically significant changes. Continued research in this area will contribute to existing knowledge and facilitate addressing needs at the end of life to maintain and improve quality of life.

Appendices

APPENDIX A

MVQOLI

Missoula Vitas Quality of Life Index

MISSOULA-VITAS QUALITY OF LIFE INDEX VERSION-25S

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INSTRUCTIONS:

Indicate the extent to which you agree or disagree with the following statements by filling in ONE of the circles along the line. For items with two statements choose a circle close to the statement with which you agree more. If you make a mistake or change your mind, mark an X through the wrong answer, and fill in the circle indicating your correct answer. Please fill in the circle completely. ●

GLOBAL

How would you rate your overall quality of life?

○ ○ ○ ○ ○
Best ← → Worst
Possible Possible

SYMPTOM

1. My symptoms are adequately controlled.

○ ○ ○ ○ ○
Agree ← → Disagree

2. I feel sick all the time.

○ ○ ○ ○ ○
Agree ← → Disagree

3. I accept my symptoms as a fact of life.

○ ○ ○ ○ ○
Agree ← → Disagree

4. I am satisfied with the current control of my symptoms.

○ ○ ○ ○ ○
Agree ← → Disagree

5. Despite physical discomfort, in general I can enjoy my days.

Physical discomfort overshadows any opportunity for enjoyment.

○ ○ ○ ○ ○
← →

FUNCTION

6. I am still able to attend to most of my personal needs by myself.

I am dependent on others for personal care.

○ ○ ○ ○ ○
← →

7. I am still able to do many of the things I like to do.

I am no longer able to do many of the things I like to do.

○ ○ ○ ○ ○
← →

8. I am satisfied with my ability to take care of my basic needs.

○ ○ ○ ○ ○
Agree ← → Disagree

9. I accept the fact that I can not do many of the things that I used to do.

I am disappointed that I can not do many of the things that I used to do.



10. My contentment with life depends upon being active and being independent in my personal care.



INTERPERSONAL

11. I have recently been able to say important things to the people close to me.



12. I feel closer to others in my life now than I did before-my illness.

I feel increasingly distant from others in my life.



13. In general, these days I am satisfied with relationships with family and friends.



14. At present, I spend as much time as I want to with family and friends.

○ ○ ○ ○ ○
Agree ← → Disagree

15. It is important to me to have close personal relationships.

○ ○ ○ ○ ○
Agree ← → Disagree

WELL-BEING

16. My affairs are in order;
I could die today with
a clear mind.

My affairs are not
in order; I am worried
that many things are
unresolved.

○ ○ ○ ○ ○
← →

17. I feel generally at peace
and prepared to leave this
life.

I am unsettled and
unprepared to leave this
life.

○ ○ ○ ○ ○
← →

18. I am more satisfied with myself as a person now than I was before my illness.

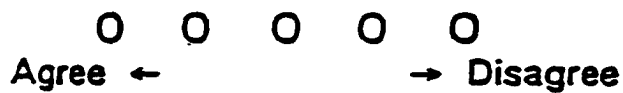
○ ○ ○ ○ ○
Agree ← → Disagree

19. The longer I am ill,
the more I worry about
things "getting out
of control".

The longer I am ill, the
more comfortable I am
with the idea of "letting
go".



20. It is important to me to be at peace with myself.



TRANSCENDENT

21. I have a greater sense
of connection to all
things now than I did
before my illness.

I feel more disconnected
from all things now than
I did before my illness.



22. I have a better sense
of meaning in my life
now than I have had in
the past.

I have less of a sense
of meaning in my life
now than I have had in
the past.



23. As the end of my life approaches, I am comfortable with the thought of my own death.

As the end of my life approaches, I am uneasy with the thought of my own death.

← →

24. Life has become more precious to me; every day is a gift.

Life has lost all value for me; every day is a burden.

← →

25. It is important to me to feel that my life has meaning.

Agree ← → Disagree

Did you complete this questionnaire by yourself?

YES NO

MISSOULA-VITAS QUALITY OF LIFE INDEX

BACKGROUND INFORMATION:

Please mark the answer that best describes you by filling in the appropriate circles.

1. Marital Status:

(For the purpose of this question, common law and same sex companions are considered as marriage partners.)

- | | |
|-------------------------------------|---------------------------------|
| <input type="radio"/> Never Married | <input type="radio"/> Separated |
| <input type="radio"/> Married | <input type="radio"/> Widowed |
| <input type="radio"/> Divorced | |

2. Religious Affiliation:

- | | |
|----------------------------------|-----------------------------|
| <input type="radio"/> Catholic | <input type="radio"/> Other |
| <input type="radio"/> Jewish | <input type="radio"/> None |
| <input type="radio"/> Protestant | |

3. Highest Education Level:

- | | |
|---|---|
| <input type="radio"/> Grade School | <input type="radio"/> Bachelors Degree |
| <input type="radio"/> High School | <input type="radio"/> Masters Degree |
| <input type="radio"/> Associates Degree | <input type="radio"/> Doctorate or equivalent |

APPENDIX B

Permission To Use MVQOLI

MEMORANDUM

INNOVATIVE HOSPICE CARE™

TO: SIDNEY BRUSH, RN
FROM: MELANIE PRATT MERRIMAN, Ph.D.
DATE: 18 March 1996
RE: USE OF THE MISSOULA-VITAS QUALITY OF LIFE INDEX

Thank you for your interest in the Missoula-VITAS Quality of Life Index. The instrument is copyrighted by VITAS Healthcare Corporation and Ira R. Byock, MD. It is available for use based on the following agreement:

1. The instrument may be copied but may not be changed in any way without prior written permission from the authors.
2. Upon return of the attached information sheet, you will receive a copy of the instrument suitable for reproduction, a separate copy of the instrument coded to show the scoring for each item, instructions for calculating dimensional subscores and a total score, and a scoring spreadsheet created in LOTUS 3.4 that can be imported into other spreadsheet programs.
3. The user will provide to the authors yearly updates regarding use of the instrument.
4. Upon request, the user will provide to the authors the QOL raw data and demographic data collected in a manner that protects patient confidentiality. This data will be used for refinements of the instrument.

Please indicate your agreement with the above by signing and returning the duplicate copy of this memo provided. Return the memo and the information sheet to:

**Dr. Melanie Merriman
VITAS Healthcare Corporation
100 S. Biscayne Blvd., #1500
Miami, FL 33131**

Signed 
Melanie P. Merriman, Ph.D.

Signed 


APPENDIX C

MVQOLI Scoring

MISSOULA-VITAS QUALITY OF LIFE INDEX VERSION - 25S

SCORING

NOTE: The score for each answer to each item is indicated on the coded version of the MVQOLI attached to this sheet.

QUESTION NUMBERS BY CATEGORY AND DIMENSION

DIMENSIONS

CATEGORIES	Symptom (Sx)	Function (F)	Interpersonal (IP)	Well-Being (WB)	Transcendent (T)
Assessment	1	6	11	16	21
	2	7	12	17	22
Evaluation	3	8	13	18	23
	4	9	14	19	24
Importance	5	10	15	20	25

Global - Separate Question at beginning.

Dimensional Subscore Calculations

Average assessment + Average Evaluation = Unweighted Dimension Score (UDS)

UDS X Importance = Weighted Dimension Score (WDS)

Calculating Weighted Dimension Scores

Symptom (Sx) $((Q1+Q2+Q3+Q4)/2) \times Q5$
 Function (F) $((Q6+Q7+Q8+Q9)/2) \times Q10$
 Interpersonal (IP) $((Q11+Q12+Q13+Q14)/2) \times Q15$
 Well-Being (WB) $((Q16+Q17+Q18+Q19)/2) \times Q20$
 Transcendent (T) $((Q21+Q22+Q23+Q24)/2) \times Q25$

Total Score

(Sum of Weighted Dimension Scores/10) + 15 = Total Score

Global Score

The Global Item is scored from 1-5 as shown on the coded form attached.

APPENDIX D

Script To Present MVQOLI

Appendix D

Script for Presenting the MVOOLI to New Hospice Patients

We are asking all new patients admitted into Hospice to complete the MVQOLI survey. It is about you and how you feel; there are no right or wrong answers. In hospice, our main goal is to maintain and improve quality of life. With this survey, we hope to demonstrate this and also look for ways to improve our program and care.

This survey is completely voluntary and if you choose not to complete it, the care you receive from hospice will not be affected. If you choose to participate, we will ask you to sign an informed consent, complete the survey by yourself and return it in the attached self-addressed envelope. Three weeks after completing the first survey, we will ask you to repeat it again. If you are troubled or concerned by any of the questions or statements in the survey, please let us know and we will have your social worker spend some time with you talking about these concerns.

You may change your mind about participation at any time. All surveys are confidential, coded by number and you will not be identified by name.

Thank you for your participation.

APPENDIX E

Consent Form

APPENDIX E

CONSENT FORM FOR PATIENTS OF HOSPICE of SOUTHWEST MICHIGAN

I understand that this is a study to find out how people like me feel about their quality of life when entering Hospice and again three weeks after being in Hospice.

I also understand that:

1. if I chose to participate that I will complete two questionnaires about my quality of life. One to be done now and then again in three weeks.
Each questionnaire will take approximately 10 to 20 minutes to complete.
2. all new patients will be asked to complete this questionnaire.
3. completing these questions will not harm me in any way.
4. my answers will not identify me as an individual and will be kept confidential.
5. I may ask for a copy of the completed results.

This study has been explained to me and the nurse has answered any questions I have.

I understand I am doing this willingly and I may change my mind at any time, with out affecting my care from Hospice Care of Southwest Michigan.

I give permission for research to release information obtained in this study and I understand that I will not be identified by name.

I may call Hospice of Greater Kalamazoo at 345-0273 if I have any further questions.

I have read and understand the above information, and agree to participate.

Witness

(Participant signature)

Date

Date

_____ I am interested in receiving a summary of the study results.

APPENDIX F

Authorization To Use Subjects



Cass County Hospice
321½ West Delaware Street
Decatur, MI 49045-1106
(616) 423-6015 phone
(616) 423-7364 fax
1-800-304-0273

Hospice of Greater Kalamazoo
301 West Cedar Street
Kalamazoo, MI 49007-5106
(616) 345-0273 phone
(616) 345-8522 fax

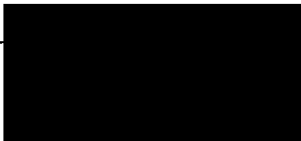
Hospice of Van Buren County
321½ West Delaware Street
Decatur, MI 49045-1106
(616) 423-6015 phone
(616) 423-7364 fax
1-800-304-0273

August 28, 1997

To Whom It May Concern:

This is to verify that Sidney Brush, R.N., B.S.N., has permission to access and analyze all completed MVQOLI surveys collected from patients admitted to Hospice of Greater Kalamazoo since April, 1996. She may use these records and results for fulfillment of completion of her thesis for Grand Valley State University.

Sincerely,



Jean M. Maile
Chief Executive Officer
Hospice Care of Southwest Michigan

/rmb

APPENDIX G

Human Subjects Review Committee Approval



1 CAMPUS DRIVE • ALLENDALE MICHIGAN 49401-9403 • 616/895-6611

February 3, 1998

Sidney Brush
2525 Highpointe
Kalamazoo, MI 49008

Dear Sidney:

The Human Research Review Committee of Grand Valley State University is charged to examine proposals with respect to protection of human subjects. The Committee has considered your proposal, "*Quality of Life in the Hospice Patient*", and is satisfied that you have complied with the intent of the regulations published in the Federal Register 46 (16): 8386-8392, January 26, 1981.

Sincerely,



Paul Huizenga, Chair
Human Research Review Committee

List of References

List of References

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