AN END-OF-LIFE SUITE IN A LOCAL METROPOLITAN AREA HOSPITAL:  
THE IMPACT ON PATIENT, FAMILY AND/OR CAREGIVER SATISFACTION,  
QUALITY OF LIFE AND A GOOD DEATH EXPERIENCE

A Research Grant Proposal

Presented to the faculty of the School of Nursing
California State University, San Marcos

Submitted in partial satisfaction of
the requirements for the degree of

MASTERS OF SCIENCE

in

Nursing
Family Nurse Practitioner

by

JoAnn Marie Adams
SPRING
2013
CALIFORNIA STATE UNIVERSITY SAN MARCOS
PROJECT SIGNATURE PAGE
PROJECT SUBMITTED IN PARTIAL FULLFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE
MASTER OF SCIENCE
IN
NURSING
PROJECT TITLE: AN END-OF-LIFE SUITE IN A LOCAL METROPOLITAN AREA
HOSPITAL: THE IMPACT ON PATIENT, FAMILY AND/OR CAREGIVER
SATISFACTION, QUALITY OF LIFE AND A GOOD DEATH EXPERIENCE

AUTHOR: JoAnn Marie Adams

DATE OF SUCCESSFUL DEFENSE:

THE PROJECT HAS BEEN ACCEPTED BY THE PROJECT COMMITTEE IN
PARTIAL FULLFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING.

[Signatures and dates]

PROJECT COMMITTEE CHAIR

PROJECT COMMITTEE MEMBER

PROJECT COMMITTEE MEMBER
Student: JoAnn Marie Adams

I certify that this student has met the School of Nursing format requirements, and that this project is suitable for shelving in the Library and credit is to be awarded for the project.

______________________________  _________________________
Amy Carney                     Date

Graduate Coordinator

School of Nursing
College of Education, Health, and Human Services
California State University San Marcos
Abstract

of

An End-of-Life Suite in a Local Metropolitan Area Hospital: The Impact on Patient, Family, and/or Caregiver Satisfaction, Quality of Life and a Good Death Experience

by

JoAnn Marie Adams

Statement of Problem

There is very little research regarding the location of death for end of life care patients, quality of life, a 'good death', and patient satisfaction. Where one dies is an important topic for the terminally ill patient and their family and/or caregiver (Feldman & Lasher, 2007). There is a concept of the terminally ill person being able to have a 'good death' which is important to this research proposal. The 'Good Death' Scale was created for acute care inpatients so providers can better understand how patient's viewed death and what they considered to be a 'good death' (Leung, Tsai, Cheng, Liu, Chiu, Wu & Chen, 2010). Where the patient dies is a factor in the 'Good Death' Scale. The goal of this proposal is to identify new paradigms regarding quality of life and patient satisfaction relating to how the patient's death is facilitated. As the population of people over the age of 75 gets larger, the need to provide options for the terminally ill person and their family will increase (Profile of Older Americans, 2011). By providing these patients with a choice, the terminally ill patient will have a better death experience, which will improve quality of life and increase patient satisfaction. This proposed research grant will allow a local metropolitan area hospital to provide two End-of-Life Suites and trained staff to care for patients, their family and/or caregivers in their last week of life. This researcher will follow the use of the End-of-Life Suites for one year gathering qualitative data regarding patient and family satisfaction, quality of life and 'good death' perception. The data collected will be shared with
local hospitals, hospice and palliative care groups, and published in a scholarly journal to improve understanding of the terminally ill person’s needs.

Sources of Data

A systematic research review was performed using CINAHL, PUBMED and Google Scholar CSMSU databases. Keywords used were: palliative care, hospice, terminally ill, quality-of-life, end-of-life, patient satisfaction, good death, patient rooms, private rooms, hospital room, inpatient and single rooms.

Amy Carney, DNP 4/29/13 Date
ACKNOWLEDGEMENTS

I would first like to thank my family and dear friends for supporting, encouraging and cheering me on in my pursuit of higher education. I appreciate their confidence in me and my abilities when I had doubts. I especially would like to acknowledge and thank my husband Dan. He has been amazingly supportive throughout this past seven years of school. He is also the one who heard the most whining, and still stayed by my side, making me dinners, helping me study and staying clear when I was stressed. Finally, I cannot go without mentioning Heather Mallon, my ‘illegitimate daughter’ and nursing school partner from day one of nursing school. Without Heather, I would not have kept my sanity. I would still be trying to figure out how to maneuver through Moodle, would have forgotten to do half of the assignments, and never really understood the true meaning of a BFF.

I am forever grateful to my preceptors Jackie Copeland, Colleen Saunders and Pat Onyegbule for an invaluable experience in learning how to care for people as a practitioner. It is truly an art form and I am blessed to have some of the best examples as teachers.

Finally, I would like to express my gratitude to my Project committee: Amy Carney, Jackie Copeland, and Debbie Bennett. Without them, this proposal would not have been possible. Also, I wish to share my sincerest gratitude to the faculty at CSUSM for their support and willingness to see each student as an individual and to make sure that we each turned into a capable, caring and well trained FNP.

Much gratitude and appreciation,

JoAnn Adams
Grant Application
Do not exceed character length restrictions indicated.

1. TITLE OF PROJECT (Do not exceed 81 characters, including spaces and punctuation.)
An End-of-Life Suite in a Local Metropolitan Area Hospital and the Impact of Pa...

2. RESPONSE TO SPECIFIC REQUEST FOR APPLICATIONS OR PROGRAM ANNOUNCEMENT OR SOLICITATION
   (If "Yes," state number and title)
   Number: XXXXXX Title: XXXXXXXXXX XXXXXXX XXXXXX

3. PROGRAM DIRECTOR/PRINCIPAL INVESTIGATOR
   3a. NAME (Last, first, middle)
       Adams, JoAnn Marie
   3b. DEGREE(S)
       BSN RN
   3c. POSITION TITLE
       Graduate Student
   3d. MAILING ADDRESS (Street, city, state, zip code)
       XXXX Buckingham Lane
       Carlsbad, CA XXXXX
   3e. DEPARTMENT, SERVICE, LABORATORY, OR EQUIVALENT
       California State University San Marcos
   3f. MAJOR SUBDIVISION
       School of Nursing
   3g. TELEPHONE AND FAX (Area code, number and extension)
       TEL: XXX-XXX-XXXX FAX: XXX-XXX-XXXX
   E-MAIL ADDRESS: XXXXXXX@cougars.csusm.edu

4. HUMAN SUBJECTS RESEARCH
   4a. Research Exempt
       [ ] No [ ] Yes
   4b. Federal-Wide Assurance No.
       [ ] No [ ] Yes
   4c. Clinical Trial
       [ ] No [ ] Yes
   4d. NIH-defined Phase III Clinical Trial
       [ ] No [ ] Yes

5. VERTEBRATE ANIMALS
   5a. Animal Welfare Assurance No
       [ ] No [ ] Yes

6. DATES OF PROPOSED PERIOD OF SUPPORT (month, day, year—MM/DD/YYYY)
   From [ ] No Through [ ] Yes
   09/01/13 09/01/14
   7a. Direct Costs ($) 7b. Total Costs ($)
       $23,690 $30,323
   8a. Direct Costs ($) 8b. Total Costs ($)
       $23,690 $30,323

9. APPLICANT ORGANIZATION
   Name CSUSM School of Nursing
   Address 333 S. Twin Oaks Valley Road
       San Marcos, CA 92096
   10. TYPE OF ORGANIZATION
       Public: [ ] Federal [ ] State [ ] Local
       Private: [ ] Private Nonprofit
       For-profit: [ ] General [ ] Small Business
       Woman-owned [ ] Socially and Economically Disadvantaged

11. ENTITY IDENTIFICATION NUMBER
    DUNS NO. XXXXXX Cong. District XXXXX

12. ADMINISTRATIVE OFFICIAL TO BE NOTIFIED IF AWARD IS MADE
    Name XX XXXX XXXXX
    Title Sponsored Project Administrator
    Address CSUSM UARC
       333 S. Twin Oaks Valley Road
       San Marcos, CA 92096
   13. OFFICIAL SIGNING FOR APPLICANT ORGANIZATION
       Name XX XXXX XXXXX
       Title XX XXXX XXXXX
       Address CSUSM
       333 S. Twin Oaks Valley Road
       San Marcos, CA 92096
   14. APPLICANT ORGANIZATION CERTIFICATION AND ACCEPTANCE
       I certify that
       SIGNATURE OF OFFICIAL NAMED IN 13. DATE
       the statements herein are true, complete and accurate to the best of my knowledge,
       (In ink. "Per" signature not acceptable.) [ ] No [ ] Yes
       and I accept the obligation to comply with Public Health Services terms and conditions if a grant
       is awarded as a result of this application. I am aware that any false, fictitious, or fraudulent
       statements or claims may subject me to criminal, civil, or administrative penalties.
PROJECT SUMMARY (See instructions):
The plan for this research proposal is to utilize funds from this grant to transform two acute care oncology hospital rooms in a local metropolitan area hospital into suites which will be primarily used for terminally ill inpatients and their families and/or caregivers. The patient must be determined to be within their last week of life by a physician or nurse practitioner and be on comfort care. Because there are no other local hospitals currently utilizing End-of-Life Suites, these rooms will be used to pursue data to get a better understanding of patient satisfaction, improved quality of life and a 'good death' relating to the use of an End-of-Life Suite. The registered nurses and certified nursing assistants will be provided a two hour sensitivity class for training regarding care for the terminally ill patient and their family and/or caregivers. Qualitative research will commence once the rooms are up and running and the staff is trained. Once permission is granted and signed consent obtained, the patient, family and/or caregivers will participate in an interview with questions relating to quality of life patient satisfaction and the perception of a 'good death'. The research will be useful in determining if the provision of an End-of-Life Suite to terminally ill patients and their family and/or caregivers increases patient satisfaction scores, improves quality of life and allows the terminally ill patient to experience a 'good death'.

Research Question
Will the provision of an End-of-Life Suite to a terminally ill inpatient and their family and/or caregiver improve patient satisfaction, quality of life and the perception of a 'good death'? 

RELEVANCE (See instructions):
The information gained from this research project will improve quality of life and a good death for terminally ill patients. It also has the potential to help hospital systems to improve patient satisfaction scores which will impact them financially.
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<th>Organization</th>
<th>Role on Project</th>
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<td>PI</td>
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<td>Jacqueline Copeland</td>
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<td>Elizabeth Hospice</td>
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**OTHER SIGNIFICANT CONTRIBUTORS**

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<th>Name</th>
<th>Organization</th>
<th>Role on Project</th>
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Human Embryonic Stem Cells  

- Yes

If the proposed project involves human embryonic stem cells, list below the registration number of the specific cell line(s) from the following list:  
  Use continuation pages as needed.

- No

If a specific line cannot be referenced at this time, include a statement that one from the Registry will be used.

Cell Line
RESEARCH GRANT

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Appendix (Five identical CDs.)

Check if Appendix is Included

* Follow the page limits for these sections indicated in the application instructions, unless the Funding Opportunity Announcement specifies otherwise.
**DETAILED BUDGET FOR INITIAL BUDGET PERIOD**  
**DIRECT COSTS ONLY**

List PERSONNEL (Applicant organization only)  
Use Cal, Acad, or Summer to Enter Months Devoted to Project  
Enter Dollar Amounts Requested (omit cents) for Salary Requested and Fringe Benefits

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**CONSULTANT COSTS**  
**EQUIPMENT (Itemize)**  
**SUPPLIES (Itemize by category)**  
Office supplies and pamphlets  
**TRAVEL**  
**INPATIENT CARE COSTS**  
**OUTPATIENT CARE COSTS**  
**ALTERATIONS AND RENOVATIONS (Itemize by category)**  
Construction and appliances—remodel two private hospital rooms into suites  
**OTHER EXPENSES (Itemize by category)**  
Sensitivity training for 24 RN's and 14 CNA's

**SUBTOTALS**  
10,900 0 10,900

**CONSORTIUM/CONTRACTUAL COSTS**  
**DIRECT COSTS**

**SUBTOTAL DIRECT COSTS FOR INITIAL BUDGET PERIOD** (Item 7a, Face Page)  
$ 23,690

**CONSORTIUM/CONTRACTUAL COSTS**  
**FACILITIES AND ADMINISTRATIVE COSTS**

**TOTAL DIRECT COSTS FOR INITIAL BUDGET PERIOD**  
$ 23,690
BUDGET FOR ENTIRE PROPOSED PROJECT PERIOD
DIRECT COSTS ONLY

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TOTAL DIRECT COSTS FOR ENTIRE PROPOSED PROJECT PERIOD $23,690

JUSTIFICATION. Follow the budget justification instructions exactly. Use continuation pages as needed.
An End-of-Life Suite

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**Budget Justification**

**Personnel Cost**

JoAnn Adams, BSN, RN, FNP-C will serve as the Principle Investigator (PI) and the responsible party as a contact for the local metropolitan area hospital, the contractor for the remodel of the hospital rooms and the staff of the floor gaining the two End-of-Life Suites. JoAnn Adams is a graduate student prepared Family Nurse Practitioner, with a focus in Palliative Care medicine and Hospice Care. She is planning to work full time with a local Hospice and will be responsible for the overall direction of the project. This will include (1) presenting the proposal of creating two End-of-Life Suites at a local metropolitan area hospital at no cost to the hospital.

This researcher feels that the oncology floor could possible best suit this proposal. They will of course lose the capacity of two rooms for acute care, but in turn will gain two suites to be utilized by terminally ill patients currently admitted to the hospital. These rooms can be used to inpatient care if there are no comfort care patients residing on the floor. The hope for the future of these rooms is that the hospital will be in contact with local palliative groups and local hospices to have access to these rooms as well. JoAnn Adams will also be responsible for (2) preparing material to train the staff of the chosen hospital floor.

The training will include sensitivity training regarding end of life care for the terminally ill patient choosing to die as an inpatient. The staff will be trained in regarding the special needs of the dying patient as well as the needs of the family and/or caregiver; including topics such as pain and symptom management, death and dying beliefs of different cultures, and pharmacology
specific to the dying patient. The training will be two hours of lecture with a power point, and an informational packet provided to encourage follow up learning as needed. Once the rooms are functional and the staff trained JoAnn Adams will begin the research aspect of this project. She will (3) present the protocol before the Institutional Review Board and once gaining approval will (4) begin obtaining consent from either the patient, family or caregiver to record an interview consisting of 4 open ended and in-depth questions touching on quality of life, end of life care, the ‘good death’ scale and overall satisfaction with the use of the End-of-Life Suite. The interviews will continue until saturation occurs or the year of research ends, whichever comes first. Finally, JoAnn Adams will (5) transcribe half of the interviews and work together with the AI to assimilate the data and formulate a presentable report. **Total Project Cost: $5,450**

Jacqueline Copeland, DNP will serve as Associate Investigator assisting in gaining consent for interviews, interviewing, and transcribing the interviews. Jacqueline Copeland will work with the PI to assimilate the data and formulate a presentable report. **Total Project Cost: $5,450**

**Supplies**

A full color tri-fold brochure describing the End-of-Life Suite and it purpose will be provided to local palliative groups and kept at the hospital for the staff and physicians to provide to prospective patients. The RN and CNA’s will be provided with a folder with information regarding the special needs of the dying patient as well as the needs of the family and/or caregiver; including topics such as pain and symptom management, death and dying beliefs of different cultures, and pharmacology specific to the dying patient. Two mini-recorders for interviews. **Total Project Cost: $120**
Alterations and Renovations

A generalized estimate was obtained from a general engineer for Genesis Inc. to convert two hospital rooms into End-of-Life Suites.

Cabinetry and countertops: Materials $680, Labor: $66/hour @ 16 hours: $ 1,056 Lighting and electrical: Materials: $325, Labor $85/hour @ 16 hours: $1,360  
Drywall repair: Materials: $100, Labor $35/hour @ 8: $280  
Paint: Materials: $144, Labor $45/hour @ 8: $360  
Single Sleeper Chair: $400

Training

A two hour training session will be provided to the RN’s and CNA’s working on the floor where the End-of-Life Suites will be created. The training will include sensitivity training regarding end of life care for the terminally ill patient choosing to die as an inpatient. The staff will be trained in regarding the special needs of the dying patient as well as the needs of the family and/or caregiver; including topics such as pain and symptom management, death and dying beliefs of different cultures, and pharmacology specific to the dying patient. The training will be two hours of lecture with a power point, and an informational packet provided to encourage follow up learning as needed. The costs for this training time include $37/hour x 2 for 24 RN’s and $15/hour x 2 for 14 CNA’s. Total Project Cost: $ 1,920
Total Costs for Project: $23,690

Biographical Sketches

JoAnn Marie Adams

**Position Title:** Primary investigator

**Education:**

<table>
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<tr>
<th>Institution</th>
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**Personal Statement:**

Before beginning nursing school I worked as a caregiver for 10 years caring people in the last few years of their life. It was then that I became passionate about taking care of people when they are dying and helping them to have a ‘good death’. Until I began researching this topic, I did not realize there is a ‘good death’ scale. After becoming an RN and taking a position as a medical/surgical staff nurse I realized that the dying inpatient does not usually have a ‘good death’ as related to the scale. I became an advocate for these patients, but felt discouraged because there was no formal training or policy to care for terminally ill or “comfort care” patients. I pursued higher education so I could have a positive impact on the dying hospitalized patient. My goal as an Advanced Practice Nurse is to improve the quality of life and end of life experience for terminally ill people, their family and/or caregivers.

**Positions:**

- **2009-2011** Medical/Surgical Staff Nurse, Kaiser Permanente, San Diego, CA
- **2011-2012** Critical Care Nurse Training and PACU Nurse, Kaiser Permanente, San Diego, CA
- **2012-Present** Telemetry/Stroke Staff Nurse, Kaiser Permanente, San Diego, CA
Training:
2012-Present Precept with J. Copeland, DNP at Elizabeth Hospice
1996-2006 Independent Caregiver at Redwood Terrace Senior Living Facility
1996-1998 Caregiver at Mountain Shadows Community Home for
Developmentally Disabled Adults

Honors:
1996 Summa cum Laude, Oklahoma Christian University, OKC, OK
2006-Present Founding member, CSUSM Student Nurse Honor Society
2009 Summa cum Laude, California State University, San Marcos
2009-Present Sigma Theta Tau, International Honor Society
2013 Summa cum Laude, California State University, San Marcos

Professional Licenses and Certifications:
California State Registered Nurse License # 755038
Stroke Certified
Telemetry Certified
Diabetic Certified
BLS, ACLS, and PALS Certified

Jacqueline Copeland

Position Title: Associate investigator

Education:
Doctorate of Nursing Practice, University of San Diego, San Diego, CA
Master of Science in Nursing, California State University Dominguez Hills,
Carson, CA
Bachelor of Science in Nursing, San Diego State University, San Diego

Personal Statement:
I am passionate about my role as a Nurse Practitioner because it allows me to provide excellent care and comfort to those patients and their families who are on the journey towards the end of life. I truly enjoy what I do, not only with caring for patients but also having the opportunity to mentor others.

**Positions:**
- Lead Nurse Practitioner
- Nurse Practitioner
- Nursing Supervisor
- Director of Nursing
- Clinic Manager

**Role Option:**
- Family Nurse Practitioner

**Professional Licenses and Certifications:**
- FNP – FNP17010
- Furnishings – 17010
- DEA – MC1817913
- Sigma Theta Tau, International Honor Society

**Resources**

The Hospice and Palliative Nurses Foundation (HPNF) facilitate graduate research by providing a grant within a research topic that pertains to palliative care. There is an annual award of $15,000. The funding period for this grant money is for 12 months from the receipt of the award. The proposals are due on or before June 1 or the respective year. The funding start date is
September 1 of the same year. This researcher’s plan is to apply for the HPNF grant to fund the RN and CNA training as well as the research aspect of this project.

In order to be eligible for the HPNA grant the Principal Investigator must hold a master’s or doctoral degree. The Principal Investigator also must be involved in some aspect of palliative and hospice care practice, research or education. As per the bylaws of the HPNF website, a final report of expenditures and a final scientific report will be submitted to HPNF within 90 days following the end of the project funding period. The HPNF also expects that the research findings will be published in a peer-reviewed professional or scientific journal.

The application will be submitted by mail to Hospice and Palliative Nurses Foundation, One Penn Center West, Suite 229, Pittsburgh, PA 15276-0100.

This researcher will apply for a second grant from The National Institute of Health (NIH) to fund the $15,323 alterations and renovations portion of this research proposal and project. The NIH provides many opportunities for funding for research. The NIH and the Administration on Aging (AoA) has an “award mechanism for translational research that moves evidence-based research findings towards the development of new interventions, programs, policies, practices, and tools that can be used by community-based organizations” to help elderly individuals remain independent (Information for Current Grantees, 2013).

The NIH and the AoA support the Small Grant Program (R03) which provides limited funding for a short period of time to support a variety of projects, including feasibility or pilot studies or the collection of preliminary data for small, self-contained research projects in order to
develop new research technology. These grants are limited to two years of less of funding, are not renewable, and fund for no more than $50,000 per year.

The grant.gov website will be utilized in order to apply for a R03 research grant.

Research Plan

Specific Aims

The goal of this proposal is to identify new paradigms regarding an improved quality of life, a ‘good death’, and patient satisfaction relating to how the patient’s death is facilitated. A ‘good death’ is related to the “Good Death Inventory”, which was developed to evaluate the perception of a good death from the patient or bereaved family and/or caregivers point of view (Miyashita, Morita, Sato, Hirai, Shima, & Uchitomi, 2008). The proposed research grant will allow a local metropolitan area hospital to transform two private inpatient rooms, most likely in the oncology unit, into two End-of-Life Suites. The grant will also allow the researcher train staff to care for patients and their family in their last week of life. This researcher will follow the use of the End-of-Life Suites for one year, gathering qualitative data via recorded, face to face interviews with either the patient, family and/or caregiver regarding satisfaction of the death experience, quality-of-life and ‘good death’ perception. The aim for the grant is to gain a greater knowledge and understanding of how a terminally ill inpatient or their family and/or caregiver will perceive the use of an End-of-Life Suite, and if their quality of life will improve. It is the hope of this researcher that after data collection and dissemination of the findings, more hospitals will implement End-of-Life Suites into their inpatient room system.
Background and Significance

About 15 percent of the American population will be over the age of seventy-five by the year 2030 (Administration on Aging, 2013). With aging comes the possibility of acquiring a chronic illness or terminal illness, which is why a focus on end-of-life needs is necessary. As the population of people over the age of 75 gets larger, the need to provide options for the terminally ill person, their family, and/or caregiver will increase. Terminally ill patients have strong views of what they want regarding their care and what they want from their caregiver (Aspinal, Addington-Hall, Hughes & Higginson, 2003). Within the terminally ill inpatient population, quality of life can be optimized by the environment. If that person is in the hospital, the environment is their hospital room. In the US, patients are reported to be consistently more satisfied with the quality of overall care when occupying single rooms (Rowlands & Noble, 2008).

If clinicians fail to address the needs of the patient coming to the end of life, the patient can experience stress and anxiety, thus diminishing quality of life and adding to caregiver stress (Lorenz, Lynn, Dy, Shugarman, Wilkenson, Mularski, Morton, Hughes, Hilton, Magilone, Rhodes, Rolon, Sun, & Shekelle, 2008). For the person who does not want to die at home, their choices are limited, so many times they die in a hospital by default. By providing these patients with the choice of dying in the hospital and not having to deal with the present acute care ‘cure’ mentality, but rather the focus be on symptom management, the terminally ill patient will have a better death experience, which will improve quality of life and increase patient satisfaction (Hermann & Looney, 2011).

The “Good Death Inventory” was developed to evaluate the perception of a good death from the patient or bereaved family and/or caregiver’s point of view (Miyashita, et al, 2008).
There are 10 core domains involved in the Good Death Inventory, and 4 out of the 10 are directly related to environment. These include: environmental comfort, dying in a favorite place, physical and psychological comfort, and having a good relationship with medical staff.

There is very little research regarding terminally ill patients, patient satisfaction, and where the patient spends their final days of life. The data gathered from this research project will be a catalyst for future research in determining if the provision of an End-of-Life Suite increases patient satisfaction scores. An improved quality of life and a ‘good death’ are intrinsically important for most people, but these are not always financial drivers. The Affordable Care Act mandates that Medicare reimbursements are to be based on patient satisfaction surveys as well as other quality care criteria (Focus on Health Reform, 2011). The patient’s satisfaction score using the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) will be directly correlated to the amount of payout from Medicare.

The significance of this grant proposal project is related to the number of people who are projected to need end-of-life or palliative care in the future, as well at the significance of patient satisfaction scores beginning to be taken into consideration in 2012 for Medicare payout (Focus on Health Reform, 2011). Hospice and palliative care has grown significantly in the US in the past 10 years and is now almost universally available to meet the needs of the country's sickest and most vulnerable patients, but end-of-life issues and still persist (Meier & Brawley, 2011).

As far as Medicare spending goes, two thirds of all Medicare dollars are spent of people with multiple chronic illnesses (Centers for Medicare and Medicaid Services, 2010). That is one of the forces behind the Affordable Care Act and the decision to tie patient satisfaction to percentage of payout (Focus on Health Reform, 2011). Quality of life for the terminally ill
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patient is of utmost significance. If the quality of life for the patient, family and/or caregiver is improved due to the use of an End-of-Life Suite then the patient satisfaction scores should increase as well. Hospital systems can utilize the information from this research project and act on those findings to implement a plan to include End-of-Life Suites among inpatient rooms.

**Preliminary Studies/Progress Report**

Quality of life is defined many ways, but most definitions have several common factors. According to Stedman’s Medical Dictionary, quality of life is a patient’s general well-being, including mental status, stress level, sexual function and self-perceived health status (Stedman’s medical dictionary, 2011). Most definitions include the idea of the perception of the quality of one’s life being of high importance. The general idea behind understanding what quality of life means to a person is that it includes the physical well-being, material well-being, social well-being, emotional well-being, and development and activity. The terminally ill patient receiving inpatient care has different needs than the acutely ill in-patient. Quality of life is an important factor for any hospitalized patient, but for the terminally ill patient, quality of life is of utmost importance (Downey, Curtis, Lafferty, Herting & Engelberg, 2010).

According to the World Health Organization (WHO), inpatient palliative care improves the quality of life of patients and their families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support to from diagnosis to the end of life and bereavement (Palliative Care, 2013). The goal of palliative care is mainly to provide relief from pain and other distressing symptoms related to chronic illness. It is intended to neither hasten nor postpone death and affirms life while understanding that death is a normal process.
In hospital palliative care teams offer a support system to help the patients and families cope during a patient’s illness and gain understanding of their illness and the progression of that illness. The palliative care program uses a team approach to address the needs of the patient and their family and offer a plan to help the patient live actively until death. It has been shown that the patient receiving palliative care actually has been shown to have a longer life with better quality than those who did not participate in a palliative care program (Meier & Brawley, 2011). The WHO has a similar statement which indicates that not only will palliative care enhance the quality of life, it may also positively influence the course of illness by managing distressing clinical complications (Palliative Care, 2013).

Many hospital systems do not provide the patients with the option for the palliative care approach. It is this situation where the terminally ill inpatient’s needs may not be met (Lorenz, et al, 2008). There is a need for more specific research regarding terminally ill inpatients. Two nonrandomized quality improvement interventions showed improved quality of life and outcomes if there are structured orders specifically for the dying patient (Lorenz, et al, 2008).

Patient satisfaction is not only important for the patient and family to have the best possible experience but also for the further payout from the government for patient care (Focus on Health Reform, 2011). The Affordable Care Act mandates that Medicare reimbursements are to be based on patient satisfaction surveys as well as other quality of care criteria. The patient satisfaction score will be directly correlated to the amount of payout from Medicare. The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey is used to discover the level of satisfaction a patient states from their hospital stay (HCAHPS, 2011).
Research Design and Methods

The initial plan for searching for and collecting evidence was to complete a thorough literature search for scholarly articles and studies relevant to the grant proposal project. A literature review should provide a critical summary of the most recent research relating to the research problem (Polit & Beck, 2012). In the past, the topic of end of life care has been under researched but due to the increase in palliative care teams and interest, recent consideration has provided the medical community with some research.

The theoretical framework for this literature review was based on the research question- Will the terminally ill inpatient, family and/or caregiver have increased satisfaction if they experience a private End-of-Life Suite in the last week of life?

End-of-Life care is a way for health care professionals to provide pain and symptom relief, spiritual and psychosocial support as well, from diagnosis to the end of life and bereavement. The availability of hospice and the palliative care team for patients with chronic or terminal illnesses has increased over the last 5 years and has been shown to increase quality of life (Hui, Elsayen, De La Cruz, Verger, Zhukovsky, Palla, Fadul, Palmer, & Bruera, 2010). The use of a palliative care team plays an important role in the outcome for the patient as far as symptom control and psychosocial support, both of which are key components in improved quality of life. There is much research regarding the improvement of quality of life for the patient who is part of a palliative care team, or has selected hospice for end of life care. There is no research indicating if the terminally ill inpatient has the same outcomes.

The definition for patient satisfaction is more difficult to narrow down. Most research focuses on satisfaction of the patient experience. There is no research specifically focused on the
satisfaction of the family and/or caregiver when the patient’s stay ends in death, even planned death. The FAMCARE-2 is a tool created to measure family satisfaction with palliative care, but is not used for satisfaction related to hospital stays (Aoun, Bird, Kristjanson, & Currow, 2010). There are several definitions of patient satisfaction so for the purpose of this research the definition of patient satisfaction using the terminology of the HCAHPS is utilized. The HCAHPS survey encompasses eight key topics: communication with doctors, communication with nurses, responsiveness of hospital staff, pain management, communication about medicines, discharge information, cleanliness of the hospital environment, and quietness of the hospital environment (US Department of Health and Human Services, 2011).

The End-of-Life Suite is terminology modeled after private inpatient rooms once utilized at Balboa Naval Hospital, San Diego, on the oncology floor. These two rooms were designated for patients during the last one to two weeks of life and their family and/or caregiver to stay. For the purpose of this research study, the term End-of-Life Suite is synonymous with upgraded private hospital room. The upgrades include adding a small “kitchenette” which includes a small refrigerator, microwave, and coffee maker, built into the sink area of the inpatient room. They will have muted colored walls, with matching drapery and art work. The lighting will be changed from fluorescent to soft lighting with a dimmer switch. There will be a sleeper sofa/chair provided for someone to sleep in the room with the patient. When the interviews are performed the informants will have an opportunity to put into words how they feel about the suites regarding patient satisfaction, improved quality of life, and a ‘good death’ as well as discussing the staff and the suite and any part of the experience they find satisfying or not satisfying.
A systematic research review was performed using CINAHL, PUBMED and Google Scholar CSMSU databases. The keywords included in the search were palliative care, quality of life, patient satisfaction, good death, patient rooms, private rooms, room, hospital room, in-patient and single rooms. First the keyword ‘palliative care’ was searched. In CINAHL 19,055 research articles containing this word were found. By adding the keyword ‘quality of life’ to the search 2,625 articles populated. With the term ‘patient satisfaction’ added to the search, 216 populated. Finally, when the keyword ‘good death’ was added to the search, 14 populated. When any of the other keywords relating to a patient room or private room was included one study from Japan populated.

The PUBMED database populated 44,586 articles with the keyword ‘palliative care’ and 6,712 articles populated when ‘quality of life’ was added. With the term ‘patient satisfaction’ was added 372 articles populated. Finally, when the keyword ‘good death’ was added to the search, 19 populated. The final search with keywords relating to a patient’s room was added two articles populated.

The Google Scholar CSUSM database initially populated about 452,000 articles with the keyword ‘palliative care’. When the key work ‘quality of life’ was added to the search there about 273,000 articles populated. With ‘patient satisfaction’ added, the search populated about 17,000 articles. Finally, with the keyword ‘good death’, 2,351 articles populated. But when the keywords relating to private patient rooms were added, no articles populated.

The exclusion criteria for the search was articles in English only because translating a study would be time consuming and could alter the actual findings in translation. A second exclusion for the search was the date of the study. The search was limited to 2002-2012 to avoid
outdated information. The studies included for consideration must have solid research, good
design, be relevant, have little bias, and be considered reliable. No opinion or case studies were
considered for review in the literature search.

Even using the three most effective databases for a complete literature search there were
just a few studies which spoke to the problem of patient satisfaction, quality of life and private
rooms while the terminally ill patient was hospitalized for end-of-life care (van de Glind, Roode,
& Goossensen, 2007) and (Rowlands & Noble, 2008). The conclusion for the literature search
for this project was that few scientific research studies were found to evaluate the effectiveness
of private rooms when thinking of family and/or patient satisfaction and the terminally ill patient
hospitalized for end-of-life care, thus the need for a qualitative research project such at this
proposal can be a needed and valuable contribution to the healthcare industry.

There were about eleven articles which discussed the findings from studies looking at
patient satisfaction and the use of private hospital rooms. In these studies it was found that at this
time only patients in the United States were statistically proven to prefer private rooms (van de
Glind, et al, 2007). Many of the studies included items such as infection control and patient
safety in the criteria, along with patient satisfaction.

The plan for this research project is to utilize the information gathered regarding patient
satisfaction, quality of life, a ‘good death’ and the use of private hospital rooms and incorporate
it with the qualitative data gathered from the interviews. The information and data can then be
appraised and synthesized and put into a useful format. In order to fully synthesize the
information found, there would need to be adequate information regarding all the key topics.
Since patient satisfaction alone has much rich research behind it, many articles were collected
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regarding patient satisfaction while in the hospital. The collection of evidence was limited to adults in an acute care setting, and excluded pediatrics and obstetrics.

Since this researcher has been collecting data and information regarding the terminally ill inpatient and palliative care patients for the past three years, there is a good amount of information and research to be synthesized with the patient satisfaction and the terminally ill inpatient as the primary focus. The goal is to incorporate the idea of patient, family and/or caregiver satisfaction and the use of private rooms, thus discovering if the terminally ill inpatient, family and/or caregiver does indeed have increased satisfaction when staying in an End-of-Life Suite.

The goal of the presentation is to inform the board of directors of the local metropolitan area hospital so they better understand the current lack of research regarding the terminally ill inpatient and how this relates to patient, family and/or caregiver satisfaction. The presentation will also include how a private room for the actively dying patient can impact quality of life and a ‘good death’. The proposal of the addition of two End-of-Life Suites will be presented as a great addition to the hospital and education of the staff as a bonus.

The plan for integrating evidence with a clinical agency is to present the findings and evidence gathered from this research project to the local metropolitan area hospital where the End-of-Life Suites are integrated. The importance and focus patient satisfaction is attracting at this time makes this qualitative study of utmost importance. The lack of research regarding terminally ill inpatients and patient, family and/or caregiver satisfaction regarding private room proves that there needs to be a research backed intervention in this area. Once the information is gathered, the interviews complete, the data analyzed and synthesized, a presentation can be
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organized to disseminate. This researcher plans to formulate a research article to be published in a scholarly journal.

The plan for the implementation of protocol for this project is to gather data from the interviews regarding use of the End-of-Life Suites.

This study lends itself to a qualitative approach which is a systematic inquiry concerned with understanding human beings and the nature of their transactions with themself and their surroundings. The research design best suited for this proposal is a phenomenological approach. Phenomenology has its roots in philosophy and psychology and focuses of the meaning of lived experiences in humans. It is an approach to understanding people’s everyday life experiences and what they mean. This approach will be used in addition to hermeneutics, which uses lived experiences as a tool for better understanding the political, cultural, social or historical context of those experiences (Polit & Beck, 2012).

Phenomenologists assume there is an essential invariant which makes the phenomenon researchable because there is a clinical truth grounded in a person’s lived experience. In depth interviews are the best way to gather data related to this clinical truth in the lived experience. When an interview is completed, it allows the informant’s time to share their experiences beyond what a questionnaire or survey could capture (Polit & Beck, 2012).

The plan for measuring the outcomes of this study is primarily to have the proposal heard from the host hospital and to publish a research article in a scholarly journal. The project could also enlighten the overseers of the hospital to desire further research regarding inpatient palliative care and how the patient’s hospital experience can be bettered. This researcher’s
ultimate goal is to have End-of-Life Suites in several hospitals for the terminally ill inpatient to utilize during the last week or two of life.

The plan for data collection includes interviewing enough participants to get adequate data for analysis. A phenomenological study relies on a very small sample of ten or fewer. For a preliminary study, five interviews are sufficient to gain enough data for analysis. Five different interviews will take place including family members of a patient using an End-of-Life Suite at the local hospital within the past three months. This sampling gives the researchers adequate information for analysis.

The criteria for choosing the sample involve the participants recently utilizing the End-of-Life Suites at the local hospital. The interviews will be completed either before the patient dies, if they are willing and mentally able, or after the patient has dies, if the family is willing to be interviewed regarding their experience while staying in the suite. Due to the sensitive nature of the interview, adequate time for bereavement will be given before initiating the consent and interview portion of this study.

The data collection is focused on the human experience of being either a patient, family member and/or caregiver and how staying in an End-of-Life Suite affects satisfaction, quality of life, and a ‘good death’ experience. Since the proposed research is using human subjects, an Institutional Review Board (IRB) approval will be obtained.

Open ended questions and in-depth conversations help the informants describe their lived experience without leading the discussion (Polit & Beck, 2012). Each interviewee is interviewed either in the End-of-Life Suite or at home and will be asked four open-ended questions. The questions are as follows: 1. I am interested in what satisfied you the most about staying in the
End-of-Life Suite - Please tell me about your experience. 2. What are your thoughts about the staff and caregiving you and your family member received while using the End-of-Life Suite. 3. Please tell me about how your belief system was supported while staying in the End-of-Life Suite. 4. Please tell me what impact you think the use of the End-of-Life Suite may (or will) have had on the dying process for the patient (or you).

The four principles of underlying trustworthiness in qualitative research are applied. These are credibility, transferability, dependability, and confirmability (Polit & Beck, 2012). Credibility is ensured by the interviewer building a relationship and using the interviewee’s home to ensure a feeling of safety. Transferability is assured by the fact that the participants are able to identify with different areas of satisfaction. Therefore, the findings can be transferred to other palliative care patients. Dependability is ensured by the researcher taking rigorous steps to discuss the findings with researchers of other fields and gathering other opinions and findings along the way. This way the findings can be found dependable in their variation. Confirmability is ensured by the researcher continuously discussing the findings during the analysis process.

Once the interviews are taken and transcribed, this researcher and the AI will use Giorgi’s phenomenological analysis (Rossi, 2010). This type of analysis involves understanding how people experience situations in the context of the lived experience. Giorgi explains this process as understanding a phenomenon as it is revealed in life and as a way to make the researchers findings more precise. In the transcription, the researcher should put into brackets their own pre-understanding of the phenomenon. For example, the researcher’s experiences, prejudices, or principles are put aside by the brackets to keep the essence of the participant’s words and thoughts pure. This researcher will implement this type of analysis by either bracketing pre-understood phenomenon or by disregarding the pre-understood phenomenon. One
of the uses for a qualitative research study is to create solutions to practical problems. The in-depth interview process is an excellent way to identify problems as well as identifying solutions to those problems.

Five steps are used to analyze the data. The first step is to achieve an overall understanding by “reading the entire transcript in order to derive a global sense of the whole” (Polit & Beck, 2012). The second step is to break the text into meaningful units by re-reading the transcripts. This helps the researcher begin to get an understanding of the basic ‘lived experiences’ that the participants shared. The third step is to examine the data and categorize themes or patterns and to organize them into coherent categories. This part of the data processing is time and labor-intensive, but is the most important step for data analysis. This step is important to reveal certain structures of the participants lived experiences and find the most prevalent ideas or “essences.” The forth step is to identify patterns and connections within the categories. The categories may be separated by relative importance, meaning that some data seems to be more prevalent than other data. A table or matrix may be created to assist the researcher in categorizing the data in this way. The fifth and final step is to interpret the data. A list can be developed listing the key points or important findings discovered while categorizing the data. This is the time when the researcher can develop an outline, diagrams, etc to add to the final presentation.

Interviewer criteria must be followed as well (Polit & Beck 2012). The interviewers will pace data collection to avoid being overwhelmed by the intensity of the data collected and the amount of information collected. The interviewers will avoid emotional involvement with the participants. This could be particularly difficult when dealing with terminally ill patients and their families due to the nature of end-of-life issues and emotionality. The interviewers will
maintain reflexivity as well, meaning that the actions or opinions of the observer can directly influence the situation, opinion or action of the one being observed. It is important for the interviewer to understand this phenomenon and interview in such a way as to not influence the informant in any way.

Another phenomenon that can happen during interviews is for the informant to change behaviors or opinions when they know they are being observed. The interviewers will be careful to maintain a non-threatening or non-judgmental atmosphere during the interview.

**Dissemination Plan**

The plan for dissemination of the data from this project is to put the study in the form of a research paper and submitted to a scholarly journal for peer review. Besides presenting the findings and proposal to the health care facility, the information could be helpful and useful for palliative care teams throughout the United States to implement in their own way. Not only could this study change the way health care systems are designing future hospitals, but also present systems could possibly make changes to patient rooms to incorporate End-of-Life Suites. The terminally ill patient and their family and/or caregiver will be the ones who benefit, which will improve patient satisfaction scores. The hospital system benefits from the improved scores and financial reimbursements. In the end, it could be a win-win for both the patient and the hospital, and could act as a catalyst for further study in this area.
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Protection of Human Subjects

An application for research involving human subjects will be initiated to protect any human subjects participating in this study. Submission to the Institutional Review Board at California State University, San Marcos as well as the local metropolitan area hospital which participates in this project will occur prior to beginning data collection.