

Exploring Extubation Within the Home Environment

by

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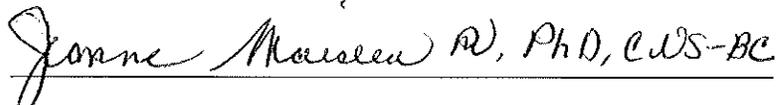
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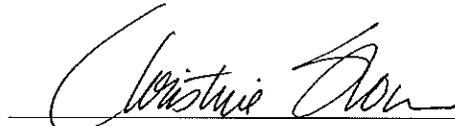
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Abstract

With the baby boomer generation getting older and having to care for their parents, it has become apparent that end of life discussions are becoming more frequent. Many elderly persons have identified that they would prefer to die in their own home. For those who are on a ventilator in the ICU, however, the option to be brought home, and subsequently extubated at home, ensuring that they will die at home has become a new phenomenon.

There is extensive published literature discussing the experiences of family members following the non-extubated death at home and on the experiences of family member's death after extubation in the hospital. What is unknown is the lived experience of those family members who experienced the extubation at home. Approximately nine adult patients with a southern Californian hospice service have experienced an extubation at home. Of the four patients who met criteria, eight family members met criteria to be interviewed. Three individuals participated in the study, with two themes and one sub-theme emerging. .

This qualitative, phenomenological retrospective study found themes of *recounting the journey* and *distrust in the medical system*, with a sub-theme of *faith as a foundation*, shedding light on the experience of the family members. These findings help healthcare providers and others gain insight into an intimate time in the lives of patients and their families.

Table of Contents

Chapter One: Introduction	1
Significance of the Problem	2
Statement of the Problem	4
Statement of Purpose	4
Chapter Two: Literature Review	5
Keyword Search	5
End-of-Life Care	6
Clinical Practice Guidelines	6
Ethical Implications	7
Advanced Directives	7
Do Not Resuscitate Orders	8
Withdrawal of Life Support	8
Location of Death	9
Identified Barriers	10
Inappropriate Transfer	10
Physician Reluctance	10
Family Involvement	11
Conceptual Framework	12
Summary	12
Chapter Three: Methods	13
Sample	13
Instruments	14

Procedure	14
Data Collection	15
Data Analysis	15
Chapter Four: Findings	16
Theme 1: Recounting the Journey	16
Theme 2: Distrust Of the Medical System	17
Subtheme 1: Faith As a Foundation	18
Chapter Five: Discussion	20
Implications	21
References	23

List of Appendices

Appendix A: IRB Approval	28
Appendix B: Demographic Form	31
Appendix C: Patient Informed Consent (Non-Drug Study)	33
Appendix D: Letter to Participants	38
Appendix E: Interview Guide	39

CHAPTER ONE

Introduction

When considering where individuals would like to spend their last days, the majority of people indicate they would like to be at home (Koffman & Higginson, 2004). For patients who end up in the intensive care unit (ICU) on a ventilator during their last moments, the choice of dying at home is either not offered or denied. Healthcare providers have the responsibility to respect and honor a patient's wishes, including where he or she has chosen to die. If a patient has made known a wish to die at home, being intubated in the ICU should not be a barrier.

One study of patients who had been compassionately extubated in the ICU found that most patients (n=375) underwent extubation within 4 days of admission (Gerstel, Engelberg, Koepsell, & Curtis, 2008). Of the 584 patients included in the study, 183 were alert and/or orientated. Unfortunately, it has been suggested that as few as 20% of hospitalized patients have advanced directives already in place (Lang & Quill, 2004), making it difficult to determine what a patient would want regarding location and intensity of care.

It has been estimated that more than 70% of people would prefer to die at home (Solloway, LaFrance, Bakitas, & Gerken, 2005). Home has been called the place of security, identity, even the "most comfortable and comforting place in the world" (Hampton, 1983, p. 1857) and it is understandable why a person would want to be at home during such a significant life event. Ideally, decisions related to preferred location of death would be made prior to reaching an imminent stage (Hampton, 1983).

Significance of the Problem

Approximately 40% of deaths occur in the hospital setting (Solloway et al., 2005), with 20% being in the ICU (Gries, Curtis, Wall, & Engelberg, 2008). Withdrawal of life support is the most common variable for the majority of deaths in the ICU (Gries et al., 2008), with an estimated 90% of ICU deaths being preceded by decisions to withdraw life support (Tonelli, 2005).

Typically, *withdrawing life support* is in reference to extubation, which has been described as the removal of mechanical ventilation (Rabow, 2010; Bos & Heim, 2010). Compassionate extubation, or terminal extubation, can be defined as the removal of mechanical ventilation at the end of life, when the goal is no longer curative, but palliative. The focus shifts to alleviating suffering in the face of a life-limiting illness or when prolonging life becomes medically futile (Curtis, Park, Krone, & Pearlman, 1995; Zier et al., 2009).

While it may be a difficult decision to intubate a patient, the decision to extubate remains a heated and delicate subject (Annells & Koch, 2001). Many factors influence the decision to withdraw life support at the end of life. In times such as these, it is the healthcare providers' responsibility to help the family make an ethically sound decision (Emanuel, Ferris, von Gunten, & Von Roenn, 2010). In some cases, patients are alert enough to make the decision themselves and can communicate their wishes (Tonelli, 2005); however, when patients cannot or have not chosen for themselves, the decision of whether to withdraw life support is typically made between the patient's family and the physician (Sizemore, 2006).

Discussions of end-of-life topics are often difficult, and most physicians tend to avoid them especially when patients are perceived as doing well (Chustecka, 2009). In Chustecka's survey of 3,960 physicians, 24% said they would engage in a discussion about where a patient would prefer to pass away only if it were patient-initiated. Forty-four percent said they would not initiate the discussion themselves or would not initiate it when a patient was first diagnosed with metastatic cancer.

The withdrawal of life support has long been an event that occurs only in the hospital ICU; in contrast, it is speculated that between 40% and 100% of people with advanced disease wish to die at home (Koffman & Higginson, 2004). As such, in very recent years, compassionate extubations have been increasingly explored and studied. Guidelines were not written until 2010 (Bos & Heim, 2010), suggesting that compassionate extubation in the home environment has become a new phenomenon. With increasing demands on hospital staff to uphold the wishes of patients and loved ones, extubation at home, an alternative to dying in the ICU, has emerged as an innovative solution.

Most studies on end-of-life extubation in the home environment have been conducted on the pediatric and neonatal population (Sine, Sumner, Gracy, & von Gunten, 2001). Very little research has been done on the adult population. A Google search of the term *compassionate extubation* drew a mere 165 results at the time this paper was written, and most of these were related to pediatric and neonatal extubation. Adult extubation within the home environment remains an emerging practice.

What is not known is the prevalence of extubations occurring in the home environment. Because most extubations occur in the ICU setting, research related to

home extubation has not yet been published. Additionally, while guidelines exist for the ICU setting, guidelines for the home environment are still being created.

Statement of the Problem

The lived experience of family members of patients who are extubated in the home environment has not yet been explored.

Statement of Purpose

The purpose of this research is to evaluate the lived experience of family members who have witnessed an extubation in the home environment. This study will include discussion of family members' overall experience.

Once explored, family members' perceptions of the event can then be compared with the perceptions of family members who have been involved with extubation in the ICU environment. This project hopes to support the importance of family inclusion in the decision-making process, understanding that all parties must be in consensus for a patient to undergo an extubation in the home environment.

CHAPTER TWO

Literature Review

While extensive research has been conducted on the experience of death both in ICU and in the home, there is a gap in the literature about extubation in the home environment. Because there is scant research on at-home extubations, research surrounding the process of passing away in the ICU and in the home was explored.

Keyword Search

The keywords *compassionate extubation* yielded very few results. The PubMed database returned only two results, both referencing pediatric populations. Other search engines and databases, such as Guidelines.gov, CINAHL, EBSCO, and Joanna Briggs Institute, also yielded few or no matches, which suggests *compassionate extubation* is a new concept or phenomenon. The term *terminal extubation* yielded better results, but searching *withdrawal of life support* significantly improved the results.

This project focuses on the decision-making process, family perceptions, perceived barriers, and the experiences of working with ICU staff prior to making the decision to extubate in the home environment.

Included in this study are end-of-life care, palliative and hospice services, clinical practice guidelines, advanced directives, and barriers to home extubation. Following a comparison of pediatric extubation and neonatal extubation is a discussion of the ethical implications of extubation. This project hopes to support the importance of family inclusion in the decision-making process and the understanding that all parties must be in consensus for a patient to undergo a compassionate extubation in the home environment.

End-of-Life Care

End-of-life care has been described as care during the end of life that primarily relates to relieving or preventing suffering with “active total care of patients whose disease is not responsive to curative treatments” (Zomordi & Lynn, 2010, p. 89).

It is estimated that 1.56 million patients received hospice care in 2009, with nearly 70% of those receiving services and ultimately dying at their place of residence (National Hospice and Palliative Care Organization [NHPCO], 2010). Of those patients, 40% passed away in their own homes, 18.9% in a nursing home, and 9.6% in a residential facility (NHPCO, 2010).

Hospice services provide medical care, pain management, and emotional support to those suffering from terminal illness; they also provide emotional and spiritual support to patients’ families (NHPCO, 2010). Hospice services are provided in a variety of settings, including long-term care facilities, hospitals, freestanding hospice centers, and at home.

Palliative care is the practice of controlling symptoms to maximize patient comfort (Institute for Clinical Systems Improvement [ICSI], 2009). When cure is no longer a viable option, palliative care often becomes the emphasis of care, focusing on the patient’s quality of life (Annells & Koch, 2001).

Clinical Practice Guidelines

Clinical practice guidelines are limited to the extubation process within the ICU setting (Truog, Campbell, Curtis, Haas, & Luce, et al., 2008). There were also guidelines for removal of the endotracheal tube (American Association for Respiratory Care [AARC], 2007). Search of the Oncology Nursing Society (ONS) and National Hospice and Palliative Care Organization (NHPCO) websites did not result in any policy or

process guidelines for extubation in the home environment. While ONS does take a stand against hastening death (ONS, 2001), neither organization establishes a definitive position on extubation in the home environment.

Ethical Implications

Decisions about end-of-life care can often be complex, challenging, and stressful for the family as well as the medical professional. In one study, 73% of surrogate decision makers for ICU patients experienced anxiety (Gries et al., 2008) about disagreements with clinicians over what each felt was best for the patient (Zier et al., 2009). When a patient cannot make his or her own wishes known, making decisions presents a difficult situation. Having an advanced directive or a Do-Not-Resuscitate (DNR) order in place can make these decisions easier (Ahrens, Yancey, & Kollef, 2003; Hampton, 1983).

Advanced directives. Documentation of a patient's wishes is crucial to preserving continuity of care (Spronk, Kuiper, Rommes, Korevaar, & Schultz, 2009). Advanced directives are legal documents that specify a patient's healthcare-related wishes, usually related to end-of-life decisions (Lang & Quill, 2004). Advanced directives may include the creation of a living will, facilitating designation of a durable power of attorney who will make decisions when the patient no longer can, and establishing goals of care (Lang & Quill, 2004). If no directive is in place, decision-making power goes to a family surrogate (Sizemore, 2006). It has been suggested that only 20% of patients already have directives in place prior to hospital admission (Lang & Quill, 2004). One study of 2,366 patients admitted into a neurosurgical ICU during a 19-

month period identified that only 17 patients had living wills or advanced directives in place (Varelas et al., 2009), suggesting that end-of-life discussions are rare.

Do not resuscitate orders. Do Not Resuscitate (DNR), or withholding cardiopulmonary resuscitation (CPR), requires a medical order and has become an acceptable practice over the past nearly thirty years, often being ordered once medical futility has been identified (Curtis et al., 1995). While the actual prevalence of DNR orders being in place prior to admission is unknown, in one study of 200 randomly selected charts, 9.7% of hospital admissions already had a DNR order in place (Curtis et al., 1995). However, once patients are admitted to the hospital, a significant increase occurs in the number of DNR orders in place. In Solloway et al.'s (2005) study of 782 patient deaths, 36% had prepared DNR directives in place the day of admission, while another 58% had them placed sometime after hospital admission.

Withdrawal of life support. A high percentage of patients who do not elect to be DNR are intubated in the ICU end up being withdrawn from life support (Spronk et al., 2009; Tonelli, 2005). Once physicians and family members engage in discussion to withdraw life support, extubation tends to happen quickly. Simmons and Parks (2008) reported that 66% of patients were extubated within 24 hours of that discussion. After extubation, the average length of survival is 7.5 hours, with at least 25% of patients passing away within an hour and approximately 69% passing away within 24 hours (Simmon & Parks, 2008). Among pediatric patients, average time to death after extubation is much shorter: between 0.5 minutes and 24 hours (mean: 80.3 minutes, median: 2.5 minutes; Garros, Rosychuk, & Cox, 2003). Another study of 27 deaths in the

pediatric ICU found that the average time to death following withdrawal of life support was 13 minutes (Moore, Kerridge, Gillis, Jacobe, & Isaacs, 2008).

Location of Death

Approximately 60% of patients receiving palliative and hospice services died at home or in an inpatient hospice facility in 2009, with only 10% dying in an acute care hospital (NHPCO, 2010). In one study of 840 patients who were extubated in the ICU, 204 had oncologic comorbidities (Gries et al., 2008). The reasons for hospitalization in this study were cardiovascular events, trauma, sepsis, respiratory failure, and pneumonia. It is not known how many patients were already receiving palliative or hospice care. Results of another study suggested that withdrawal of life support accounted for at least 10% of all ICU admissions (Varelas et al., 2009). Often, when patients do not die within a few hours of extubation, they are moved out of the ICU environment to a lower acuity hospital floor (Varelas et al., 2009; Spronk et al., 2009). Involving palliative and hospice services appears to increase the likelihood of patients being able to die at home or in their preferred environment.

One study showed that of 32 patients who identified their preferred location of death, nearly half (n=15) did not die in that location, instead dying in a hospital. In the same study, only 29 of 70 cancer patients died in their homes (Townsend, Frank, Fermont, Dyer, Karran, Walgrove, & Piper, 1990). Another study found that only 18 of the 34 patients who identified a desire to die at home actually died at home (McWhinney, Bass, & Orr, 1995). This suggests that even when patients' wishes to die at home are identified, these wishes are not always honored.

Approximately 25% of all deaths in the United States occur in or immediately after being admitted into the ICU (Gerstel et al., 2008). Dying in the ICU, however, can be perceived as impersonal and invasive, and family members tend to be less satisfied with care received in this environment (Gries et al., 2008; Norton, Tilden, Tolle, Nelson, & Eggman, 2003).

Identified Barriers

Some barriers to extubation in the home environment were identified throughout the literature. The most common barriers were lack of advanced directives (Badger, 2005; Curtis et al., 1995; Koffman & Higginson, 2004; Solloway et al., 2005), inappropriate transfer from homes or care facilities into the hospital setting (Amella, 2003), physicians' reluctance to discuss end-of-life care (Chustecka, 2009), and family members not being involved in end-of-life conversations (Zier et al., 2009).

Inappropriate transfer. Patients are often inappropriately transferred to an acute care facility and ultimately into the ICU when advanced directives are not in place (Emanuel et al., 2010). This then leads to difficult conversations in which family members are pressed to make decisions about what they think their loved one would have wanted done or not done (Gries et al., 2008; Lang & Quill, 2004).

Physician reluctance. Having end-of-life discussions is difficult for physicians (Chustecka, 2009; Norton et al., 2003). Family members have reported that it is often up to them to initiate the discussion and indicate that they want straightforward information (Norton et al., 2003). In one study 3,960 physicians were asked when they would bring up end-of-life discussions and nearly half said they would not bring up hospice care until there were no further non-palliative treatments; another 18% said they would wait until

the patient had unpleasant symptoms such as pain, nausea or vomiting (Chustecka, 2009). Further, only 55% of physicians even felt comfortable discussing end-of-life care, which implies that nearly half are not comfortable having such discussions.

Family involvement. When patients are in the ICU, including family becomes difficult due to the sheer volume of staff members involved and the complex rotation schedules of ICU medical staff, attending physicians, and ancillary support (Ahrens et al., 2003). It becomes crucial for the family members to be involved during the decision making process because physicians typically influence the ultimate decisions made (Hampton, 1983; Simmon & Parks, 2008).

However, the stress of being the decision maker may hamper the decision making process if family members need time to adequately prepare for the decision to withdraw life support or make a patient DNR (Gries et al., 2008). Family members tend to be untrusting of physicians' ability to prognosticate, and are reluctant to engage in discussion of end-of-life care when they do not feel the physician is "right" (Zier et al., 2009). In Zier's study, 60% of surrogate decision makers said they would continue with life support given only a 10% chance their loved one would survive; more than 30% said they would continue life support even given only a 1% of survival (Zier et al., 2009). The researchers identify the most common reasons for wanting to continue life support as the need to see for themselves the futility in continuing, a faith that God would intercede, and belief that the physicians were unreliable (2009). Knowing this, including family members early in the decision making process should increase satisfaction with outcomes (Norton et al., 2003).

Conceptual Framework

This study explores the lived experience of family members of patients who die after an extubation in the home environment. This phenomenological, qualitative study utilizes Myra Levine's conservation model to describe the lived experience. Focus is on the person's wholeness as perceived by the family members, which is congruent with Levin's conservation model (Polit & Beck, 2008).

This study will apply grounded theory to explore and help identify themes in the concerns and experiences of family members as they emerge through open question interviews.

Summary

When compared with the possibility of death in the busy environment of the ICU, the option of dying at home is often perceived as more comfortable and therefore the preferred location of death (Koffman & Higginson, 2004). It has been suggested that the home environment is preferred because it is more peaceful, familiar, and supports a higher level of dignity (Teno et al., 2004). If upon withdrawal of life support the patient is expected to die, then bringing the patient home prior to the removal of life support would enhance the patient's ability to die in his or her preferred location.

CHAPTER THREE

Methods

This was a phenomenological qualitative study utilizing an open ended, semi-structured interview technique to explore the lived experience of extubation in the home. (Appendix A).

Sample

Participants in this study were family members of patients who died in their homes subsequent to a home extubation. A convenience sample of medical charts of patients who died while on San Diego Hospice services was reviewed to identify family members listed under “Family and Friends” section of the chart. Family members were those related to the patient either by blood or by marriage, including individuals in older, younger, and same generations. Inclusion criteria were that family members were over the age of 18, were able to understand English, were present at the time of extubation, and lived in San Diego County.

A convenience sample was chosen by determining the number of individuals listed in the medical record. In the initial sampling of 14 charts of patients who underwent “withdrawal of life-sustaining support at home,” 48 individuals were listed under the “Family and Friends” section. Upon further review, four of the 14 patients had experienced an extubation. Other withdrawals included stopping left ventricular assist devices (LVADs), insulin drips, Bipap, and cardiac vasopressor drugs. Of the individuals listed in the “Family and Friends” section of the charts of the four patients who experienced an extubation, eight met the criteria to be contacted about the study.

One individual declined to be interviewed citing that it was too emotional and difficult to discuss. Three individuals did not return messages left requesting their participation. One individual agreed to be interviewed but did not meet at the specified time and location, which was at the individual's home, and did not return subsequent calls. Three individuals agreed to participate and subsequently completed the interview.

Instruments

Interviews of family members were recorded with a digital audio recorder. The interviews were then transcribed into an electronic document and a secondary person verified accuracy. After transcription, the data was analyzed to identify common themes. For confidentiality preservation, the data will be kept in a locked file for five years, and then destroyed. Actual audio of the interviews was destroyed immediately after verification of transcription accuracy.

Study Procedures

Once participants were identified and permission was obtained, the family members selected for the survey were contacted by phone about participating in the study. Those who agreed were mailed a letter with statement of intent, demographics, and consent for interview. They were also given the choice of being interviewed in their own homes or in another location, such as San Diego Hospice or at Point Loma Nazarene University. After interview times were confirmed, just prior to the interview the participants were asked to sign an informed consent to be interviewed and to have their conversation recorded. Each participant was given an identical copy of each consent signed. Each participant was assigned a study number to protect anonymity. Internal

Review Board (IRB) approval was obtained through Point Loma Nazarene University as well as San Diego Hospice and the Institute of Palliative Medicine (Appendix A).

Data Collection

A digital voice recorder recorded the interviews. Ten open-ended questions served as an interview guide (Appendix E), and the interviewee was given ample time to respond to each question. Simultaneous processing of information introduced further questioning for clarification and to capture each participant's perceptions. Data was solely obtained by the interviewer. After the interviews, the recorded discussions were transcribed electronically and reviewed for accuracy by the interviewer.

Data Analysis

Listening to the subjects and simultaneously recording the interviews allowed for interpretation and later, a more specific organization, of themes that emerged in participants' perceptions of the at-home extubation experience. Peer review of participants' perceptions and overarching themes identified helped to further support validity of results.

CHAPTER FOUR

Findings

Data analysis revealed two prominent themes and one sub-theme. The themes were *recounting the journey* and *distrust of the medical system*. The sub-theme that emerged was *faith as a foundation*.

Theme 1: Recounting the Journey

When prompted, “Tell me about your experience,” the participants each first described the journey leading up to the extubation. Each participant described the patient’s background and his or her own previous beliefs, with their thoughts as to why the patient chose to undergo the extubation. Rather than directly recounting the details of the extubation, participants described their struggles during their loved ones’ decline in health and physical abilities, contrasting the patients’ earlier robust health with their weakened states at the end. Participants also pondered the choices made along the way that led to the decision to extubate and spent a great deal of time describing how long the patients fought with their respective illnesses. They described things that patients could or could not do at the end and even recounted conversations they had with the patient or overheard. Participants discussed at length their experiences in the hospital and between hospitalizations.

For participants, the journey leading to the extubation seemed to be of greater importance than the actual extubation. Little time was spent on recounting the actual extubation or the hospice team. When discussing these events Participant #3 said, “*hospice was a wonderful experience, I would recommend it to everybody,*” and “*it’s kind of a blur to me...I really don’t remember too much of it.*”

Participants described the extubation experience as peaceful and viewed it as a relief. Participant #2 shared, *“I was afraid that he’d be gasping for breath and it would be kinda violent and traumatic, and it wasn’t like that at all. It was very peaceful.”* Family members expressed relief for the end of the patients’ struggles and suffering, and voiced their feelings that they had done everything possible to save their loved ones, and their journey prepared them for the extubation, which could then be viewed as a positive experience. Participant #2 also said,

I saw what my dad was going through, and then I realized I really understood...and I just didn’t really understand that until I went through that. That’s why he was so able and willing to say, “ok, the time is now.”

This response reflects Zier et al.’s findings that the family needed to see the futility for themselves (2009).

Theme 2: Distrust Of the Medical System

Along with sharing their extensive recollection of the journey leading up to the extubation, participants’ responses reflected anger and a blatant distrust of the medical system. According to Participant #3, *“I had that [anger] early on because I was dealing with those stupid doctors. I was furious all the time. Just absolutely boiling inside.”*

Family members felt the medical community did not know how to care for the patients or did not know about the medical diagnosis. Participant #2 responded, *“So we had to come in and say, ‘This med isn’t being given at the right time or the right dosage or whatever,’”* and *“It was a wakeup call to realize while you’re in the hospital you need someone there 24/7 to make sure you get your medicine.”* These statements support Zier

et al.'s findings of a belief that "physicians' predictions may be unreliable" (2009, p 115). As Participant #2 expressed, "*Even in the ICU it's shocking what they miss.*"

Considering that studies suggest physicians are already reluctant to have end-of-life conversations (Chustecka, 2009), families can feel that they are not being told the truth or are not being given all available options. According to participants, the family members took it upon themselves to research the disease process. They reported feeling they were the ones who could save the patient; Participant #3 said, "*We're walking encyclopedias.*" When given the patients' prognoses, or told that patients were not doing well, the family responded strongly: Participant #3 recalled, "*I screamed, I was so mad. I said, 'You are so frigging wrong! And we are going to prove it!'*"

Participants felt the entire process was a fight against the medical community, which included the doctors, nurses, and insurance companies. This supported research findings that families felt the need to continue life support to see the futility for themselves rather than trust medical opinions (Zier et al., 2009).

The combined effect of physicians' reluctance to engage in end-of-life conversations, family members' reluctance to accept the physicians' medical opinions, and family members' need to see the futility for themselves adds credence to the theme of mistrust of the medical system.

Subtheme 1: Faith As a Foundation

All of the participants pointed to their faith as a major influence in their experience. Participant #1 also described his experience as being "*viewed through a lens of hope.*" Participant #3 observed that faith and "*knowing where [a person] is going*" made the decision to extubate much easier. Each participant stated that the patients knew

where they were going, which led to the participants' feeling relief after the patients died. Participant #1 noted, "*He was completely assured of where he was going...He had no doubt.*"

It was reassuring for the family members to know patients' ultimate fate, and faith in the afterlife gave them future hope. Participant #2 shared that having faith enabled the family to understand why the patient "...*was so able and willing to say, 'Okay, the time is now.'*" Participant #1 shared that because of faith "*You have an opportunity and a hope to see your loved ones again.*" These responses support Zier et al.'s (2009) finding that families have faith that God will intercede, in this case the intercession being giving the peace of passing on from life.

Faith as a foundation helped participants find greater strength in their spiritual ties. Each identified that the journey leading to the decision to extubate was difficult, even horrific, and that faith was essential to that experience. Participant #3 stated, "*I can't imagine going through that without faith*" and also said, "*I had to give it to the Lord and say 'Please help me with this.'*"

Having faith as a foundation increased participants' satisfaction with the decision-making process, the final decision to extubate, and ultimately, with the patients' passing away at home as they wanted.

CHAPTER FIVE

Discussion

While this was a pilot study, there are important implications for nurses. Healthcare providers should give open attention and support to the patients' family members, understanding that patients are not alone in their medical care journeys. By affirming and clarifying patients' and families' hopes and goals, providers can help swiftly make plans that are comforting for all involved when the time comes to make an end-of-life decisions.

One limitation of this study is the small sample size. If the option to extubate at home were offered and accepted in more instances, research could potentially explore additional experiences to further explain the phenomenon. One suggestion would be to present at-home extubation as an option when discussions of end-of-life care are approached. Recommendations for further research also include interviews being conducted a year or more following the extubation to allow family members ample time for grieving. As Participant #3 shared, *"The first year, you are just grieving."* Additionally, it may be more appropriate for bereavement counselors to interview the participants, as they may have already developed a relationship with the participants.

Interviews with family members revealed that the actual experience of extubation at home was less significant than the journey leading to the decision to extubate. As participants shared, the decision itself became easy once all other options were exhausted and the family felt relieved and satisfied with the decision as well as the actual extubation. This suggests that being given the option of home extubation might give family members a sense of control and comfort with the decision. This may be especially

true when the patients are able to be involved in the decision-making process. Further, the patients' ability to choose at-home extubation for themselves may relieve any possible guilt family members have about making the decision for patients.

Current data on self decision-making versus family decision-making is lacking, and further research may help clarify this surrogate phenomenon. As one study suggested, family members had a much more difficult time making decisions if the subject of end of life care had never been broached in conversations with the patient and when the patient's desires were unknown (Gries et al., 2008). While possibly difficult, conversations surrounding end-of-life care ultimately make decisions easier and give those making the decisions peace of mind.

Implications

Family members' underlying distrust of the medical system and healthcare providers' tendency to avoid communication about end-of-life topics are indicators that medical personnel should breach end-of-life conversations earlier – ideally, when situations are calm and do not yet require a decision. During these times, patients can deliberate about their decision and share it with their families and healthcare providers. By having clarity at the end of life, time and energy can be focused on supporting wishes, rather than on the stress of guesswork, thereby improving patient outcomes and family satisfaction.

This study revealed two themes of recounting the path leading up to the decision and distrust of the medical system. Healthcare providers are hugely influential in the journey a patient travels. Being open, honest, and caring can help make that journey easier for patients and their families. Asking questions to determine patient values and

goals may make the end more peaceful, rather cause families to frantically guess what patients would have desired. Once goals are known, healthcare providers, patients, and their families can move smoothly together toward achieving them. Implementing advanced directives and opening the doors of communication are the first steps to helping patients who want to pass away at home accomplish this goal with at-home extubation if desired.

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APPENDIX A

IRB Approval

**PLNU IRB
Expedited Review
1068**

Friday, June 1st, 2012

PI: Laura Spriggs, RN

Additional Investigators: N/A

Faculty Advisor: Dr. Jeanne Maiden

Title: Exploring extubation in the home environment.

The research proposal was reviewed and verified as an expedited review under category 7 and has been approved in accordance with PLNU's IRB and federal requirements pertaining to human subjects protections within the **Federal Law 45 CFR 46.101 b.** Your project will be subject to approval for one year from the June 1st, 2012 date of approval. After completion of your study or by June 1st, 2013, you must submit a summary of your project or a request for continuation to the IRB. If any changes to your study are planned or you require additional time to complete your project, please notify the IRB chair.

For questions related to this correspondence, please contact the IRB Chair, Ross A. Oakes Mueller, Ph.D., at the contact information below. To access the IRB to request a review for a modification or renewal of your protocol, or to access relevant policies and guidelines related to the involvement of human subjects in research, please visit the PLNU IRB web site.

Best wishes on your study,

Ross A. Oakes Mueller, Ph.D.
Associate Professor
Department of Psychology
IRB Chair

Point Loma Nazarene University
3900 Lomaland Dr.
San Diego, CA 92106
619.849.2905
RossOakesMueller@pointloma.edu



March 21, 2012

Laura Spriggs, RN, BSN
4311 Third Ave.
San Diego, CA 92103

Subject: **STUDY APPROVAL (CONTINGENT APPROVAL REMOVAL) –
Study #11-001-NR: Exploring Extubation in the Home Environment**

Dear Ms. Spriggs:

The IRB Chair or his/her designee had the opportunity to review the modifications that were recommended and outlined in the contingent approval letter dated February 20, 2012. The revisions have been accepted and the IRB approved documents are listed below.

- Protocol, including appendices, dated 2/14/2012, along with attachments
- Informed Consent,
- HIPAA Authorization for Research purposes
- Patient's Bill of Rights

Approval for this site will expire on **March 20, 2013**.

As a reminder, any modifications to the protocol must be approved by the IRB prior to their implementation. Any forms, except Case Report Forms, to be used during the study, or any advertisements, must be approved by the IRB prior to their implementation. Please contact this office directly at 619-278-6482 should you have any questions.

All Serious **and/or** Unexpected Adverse Events must be reported in a timely manner. Please refer to 21 CFR Part 312, §312.32 IND Safety Reports if you are not sure what constitutes a Serious or Unexpected Adverse Event.

All protocol deviations or exceptions should be reported to the IRB in a timely manner:

- **Deviation is defined as** an incident involving noncompliance with the protocol, but one that typically does not have a significant effect on the subject's rights, safety, welfare, and/or integrity of the resultant data. Deviations may result from the action of the participant, investigator or staff.

Approval Letter – Initial Review
Study #11-011-NR

Page 2
March 21, 2012

- **Exception is defined as** accidental or unintentional changes to the IRB approved protocol procedures without prior sponsor or IRB approval. Violations generally affect the subject's rights, safety, welfare, and/or the integrity of the resultant data.

Also you will be required to obtain annual review, "*An IRB shall conduct continuing review of research covered by these regulations at intervals appropriate to the degree of risk, but not less than once per year.*" [Title 21 Part 56, Section 56.109(f)].

When your study has completed you will be required to complete a Final Study Closure Report – this can be obtained at this office. This will be accompanied by a closeout letter.

The San Diego Hospice IRB is in compliance with Good Clinical Practices, the Common Rule [Title 45 CFR Part 46], the Declaration of Helsinki, the Belmont Report and the regulations set forth by the Food and Drug Administration and all amendments thereto, contained in Title 21 of the Code of Federal Regulations, Parts 50, 56 and 312.

Please contact this office for any matters that you are unsure of by calling 619-278-6482.

Sincerely,



Steve Oppenheim, MD
IRB Chair

SO/sw

APPENDIX B

Demographics Form

Directions: The following questions are in regard those who are participating in this study. All answers will be kept confidential. Please circle you response or fill in the blank. You may decline to answer any or all of the following questions.

1. What is your age? _____

2. What is your sex? _____

3. What best describes your ethnic group?

- a. Hispanic
- b. Black (non-Hispanic)
- c. White (non-Hispanic)
- d. Asian/Pacific Islander
- e. Multi-ethnic
- f. Other

4. Were you the primary care provider? Yes or No

If no, who was the primary care provider? _____

5. What is your highest level of education completed?

- a. Less than high school
- b. High school
- c. Some college
- d. Bachelors degree

e. Post graduate work

6. Do you live in the home where the patient was extubated?

Yes or No

7. What was your relationship to the patient?

8. What is your religion (if any)?

9. What is your marital status?

- a. Married
- b. Widowed
- c. Divorced
- d. Single (never married)
- e. Domestic partnership

APPENDIX C

PATIENT INFORMED CONSENT DOCUMENT**(NON-DRUG STUDY)****PROTOCOL TITLE:**

Exploring Extubation in the Home Environment.

**PRINCIPAL
INVESTIGATOR:**

San Diego Hospice & The Institute for Palliative Medicine
4311 Third Avenue
San Diego, CA 92103

PI Phone:

619 849-2927

PI Fax:

619-278-6147

PI Email Address:

Lespriggs2012@pointloma.edu

Please read this form carefully before you agree to take part in this study. It contains facts to help you decide if it is in your best interest to take part in this study. This form may contain words you do not know. Please ask the study staff to explain anything you do not understand.

INTRODUCTION:

Laura Spriggs, RN, is a registered nurse at San Diego Hospice and The Institute for Palliative Medicine and a master's student at Point Loma Nazarene University, School of Nursing. She is doing a study to find out what the at-home extubation experience was like for you as a family member. By being a part of this study, you will help health care providers gain insight about how to make end-of-life experiences better and you will also help others like yourself who may go through a similar experience.

Before you decide whether or not to participate in this study, we would like to let you know about the study, how taking part in this study may or may not help you, any benefits and/or risks to you, and what is expected of you. This process is called informed consent.

PURPOSE OF THE STUDY

The purpose of this study is to learn more about the end stage of life experiences in the hospice patient population. We also hope to learn how to provide better care and support for hospice patients by hearing your thoughts and emotions about the compassionate extubation of your loved one.

How long will I be in the study?

You will have one visit that will last anywhere between 60 and not more than 120 minutes.

How many people will take part in the study?

Approximately 18 people.

WHAT IS INVOLVED IN THE STUDY?

If you agree to participate in this study, you are agreeing to:

1. Meet with the researcher to see if you are interested in taking part in this study. You and the researcher will review this informed consent document and the researcher will answer any questions you might have about the study and your participation in it. If you are interested in taking part in this study, you will sign this informed consent document, which indicates your approval to be part of the study.
2. The interview will take place after you sign this informed consent document. The interview process consists of the following:
 - a. You will be asked some background questions, such as your age, religious affiliation, etc. You do not have to answer these questions if you do not wish to.
 - b. Your interview will be audio taped.
 - c. You will be asked some questions by the researcher, and you are free to express your thoughts and emotions in response to those questions.

AUDIOTAPE RECORDING RELEASE CONSENT FORM

As part of this study, you will have your voice recorded (audio taped) during the visits.

This is completely voluntary and up to you. You may ask to stop the taping at any time or to erase any portion of your taped recording.

I give my permission to be audio taped: Yes No

I wish to remain anonymous: Yes No

I wish to remain anonymous, but you may refer to me by a pseudonym (made up name): Yes No

The pseudonym I choose for myself is: _____

You may quote me and use my first name: Yes No

WHAT ARE THE RISKS/DISCOMFORTS OF THE STUDY?

There are no likely risks to your taking part in this study. You may become tired during the interview process, but you always have the option to stop the interview at any time.

Because of the sensitive nature of the conversation, emotions may surface during the dialogue. If at any time you need to take a moment, you may do so. You also have the option to stop the conversation and/or withdraw from the study at any time. We are

happy to connect or reconnect you with a bereavement councilor if you would like. Should you have an emotional response that you would like support with, you can call The Center for Grief Care and Education at 1-619-278-6529 or Access Crisis Hotline at 800-479-3339.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

By being a part of this study, you will help health care providers gain insight about how to make end-of-life experiences better, and you will also help others like yourself who may go through a similar experience.

Participation in this study is voluntary; you may stop the interview at any time without penalty. You may request a copy of your interview and the study's results or may voice any questions or concerns about the study by contacting Laura Spriggs at lespriggs2012@pointloma.edu, or Jeanne Maiden at jeannemaiden@pointloma.edu or call 619-849-2710.

WHAT ARE THE COSTS?

There will be no charge to you for taking part in this study.

PAYMENT FOR PARTICIPATION

You will receive a \$5.00 Starbuck's gift card for taking part in this research study.

WHO PAYS FOR STUDY RELATED ILLNESS OR INJURY?

Accidents can occur in any study and every effort will be made to treat any injuries that result from this study. The Institute for Palliative Medicine will provide medical and supportive care for any harm that happens to you from being in this study. **The Institute for Palliative Medicine at San Diego Hospice has not set aside funds to pay you for other costs if you are injured.**

WHAT ABOUT CONFIDENTIALITY?

There is a risk associated with the loss of privacy or confidentiality. We feel that the risks of something like this happening are very small because we have put into place strict privacy and confidentiality procedures for this study. Research records will be kept confidential to the extent allowed by law. The data files for this study will be kept in a locked office in a locked file cabinet and in a password protected computer file.

Use of Audio Recordings

Audio recording is necessary for this project so that the researcher can record all conversations accurately and completely. The audio-recordings will be kept private and confidential and will be stored in a locked office and a password-protected file. There is a minimal risk that your identity could be revealed through the audio recordings. However, the researcher will change names and any identifying information in any written research findings such as articles or books. The audio-recordings will be destroyed after verifying the transcription.

CONTACT FOR QUESTIONS

Participation in this study is voluntary; you may withdraw at any time without penalty. You may request a copy of your interview and the study's results or may voice any questions or concerns about the study by contacting Laura Spriggs at lespriggs2012@pointloma.edu, or Jeanne Maiden at jeannemaiden@pointloma.edu or call 619-849-2710

CAN I STOP PARTICIPATING IN THE STUDY?

You are free to join or not join the study. Please tell the researcher if you wish to no longer participate in the study.

WITHDRAWAL

The researcher has the right to stop the study at any time. She can stop the study with or without your consent if you are unable to complete the interview.

Please note that The Institute for Palliative Medicine Institutional Review Board (IRB) has signified by the Committee's stamp that it has approved this informed consent form. The IRB will review the consent form each year. The form expires on the date that is on the stamp.

An IRB is a group of doctors, nurses, and laypersons that review a research plan with the aim of protecting study participants from harm.

PATIENT CONSENT AND LEGAL RIGHTS

- I state by my signature below that I have read and understand the information above.
- I know the conditions and procedures of the study.
- I know what the possible risks and benefits are from taking part in this study.
- I know that I do not give up my legal rights by signing this form.
- I know that I will receive a signed and dated copy of this consent form as well as a signed and dated copy of “The Research Subject’s Bill of Rights”.

Printed Subject’s Name

Subject’s Signature

Date/Time

Printed Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date/Time

APPENDIX D

Letter to Participants

February 8th, 2012 [date]

Dear [participant name],

Thank you for your interest in participating in this explorative study. This study seeks to understand what the at-home extubation experience was like for you as a family member. By being a part of this study, you will help health care providers gain insight about how to make end-of-life experiences better, and you will also help others like yourself who may go through a similar experience.

By agreeing to participate, you are agreeing to meet with me and answer questions about your experience. Our conversation will be recorded on a digital voice recorder, and may take up to, but will not be longer than, two hours. Because of the sensitive nature of the conversation, emotions may surface during the dialogue. If at any time you need to take a moment, you may do so. You also have the option to stop the conversation and/or withdraw from the study at any time.

When we meet, you will be read an informed consent, and we can further discuss any questions or concerns you may have prior to starting the study.

Your interview will be transcribed by the researcher. The transcribed conversation will be password protected and the audio recording will be kept in a locked room. The audio recording will be deleted after transcription accuracy is verified.

Participation in this study is voluntary; you may withdraw at any time. You may request a copy of your interview and the study's results or may voice any questions or concerns about the study by contacting Laura Spriggs at lespriggs2012@pointloma.edu or Jeanne Maiden at jeannemaiden@pointloma.edu or by calling 619-849-2710.

Thank you again for your interest and participation in this study.

Sincerely,

[to be hand signed by...]

Laura Spriggs RN

APPENDIX E

Interview Guide

Exploring Extubation at Home

1. Tell me about your experience.
2. What do you remember most?
3. How did you feel before/during/after the experience?
4. What was important about this experience?
5. Tell me about your thoughts before/during/after the experience?
6. What would you want others to know about this experience?
7. What did you learn from this experience?
8. How did this experience impact you?
9. Why was this experience important?
10. If you were to go through this experience again, tell me if and how you would do things differently or the same.