

CAN WE TALK? DELIVERING BAD NEWS IN HAWAI'I:
SUPPORT FOR EDUCATIONAL INSTRUCTION IN PATIENT-CENTERED
COMMUNICATION

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Dedication

To Dad, with love.

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The completion of this project would not have been possible without the enormous support of many individuals. What started off as an idea turned into a yearlong project that resulted in transformational learning and personal growth.

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James, thank you for always being there and believing in me. *I love you more.*

Abstract

Giving bad news is difficult and a daily part of a health care professional's job. Yet most do not have a clear strategy or specific educational training on how to deliver the upsetting news. The purpose of this project was to learn how health care professionals can improve their communication skills when delivering bad news about a person's health. This study aimed to learn from patients' stories of a chronic disease diagnosis and of the real-life experiences of health care professionals and nursing students. Centering on informing health care providers and educators of the gap between what patients experience and what professional caregivers and nursing students learn from their educational training in Hawai'i, this research focused on a patient-centered concept that emphasizes culturally responsive care in this specific health context. Semi-structured interviews were conducted with those that had been diagnosed with a chronic disease and qualitative questionnaires were distributed to health care professionals and nursing students. This study supports health care professionals' practice of communicating empathy and learning about a patient's personal and cultural values to contribute towards providing patient-centered care.

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Chapter One

Introduction

In a technologically advanced society where there is an increasing identification of medical diseases and more detailed diagnoses, I argue in this study, that a valuable contribution to the fields of communication studies, health, and education is the topic of communicating bad news. Giving bad news to patients is difficult and a daily part of a health care professional's job.¹ As a communication studies instructor, it was only after I experienced the trauma of supporting a loved one through the medical process of a cancer diagnosis, did I realize how important communication skills can be in providing a positive or negative experience for the patient and family.

We know that chronic medical conditions occur in the United States on a daily basis. For example, cancer is the second most common cause of death behind heart disease (American Cancer Society, 2016). The American Cancer Society (2016) estimated that for 2016, 1.7 million people were newly diagnosed with cancer and approximately 600,000 people died from cancer. In Hawai'i however, cancer is the most common cause of death. It is estimated that in 2016, there were 6,850 new cases of cancer and that 2,480 died from cancer (American Cancer Society, 2016). Yet, as of April of 2016, there are 36 active oncologists in Hawai'i (Statista, 2016). With new cases of cancer diagnosis in Hawai'i occurring in thousands, it is likely that each oncologist in Hawai'i will give a bad news diagnosis very often.

Due to the prevalence of cancer rates in particular, it is likely that patients will learn of their life changing diagnosis from their physician. However, it is noted in

¹ Baile, Lenzi, Parker, Buckman, & Cohen (2002) report that most health care professionals in the U.S. will communicate bad news about 35 times a month.

research that medical doctors do not possess good communication skills (Garg, Buckman & Kason, 1997; Harden, 1996; Maguire & Pitceathly, 2002) and most health care professionals in clinical practice have not been taught strategies of breaking bad news (Buckman, 1992). Thus, many physicians do not have an approach to deliver this information. This calls for additional communication skills training and education for medical professionals, including physicians (Baile, Buckman, Lenzi, Globber, Beale & Kudelka, 2000; Brown, Parker, Fuber & Thomas, 2011; Buckman, 1984; Garg et al., 1997). Informing patients of bad news is a difficult communication task because it not only deals with the verbal component of actually giving the news, but it requires a range of communication skills, including responding to a patient's emotional reactions, involvement of family members, and decision making during an especially vulnerable time (Baile et al., 2000).

Traditionally, physicians focused on basic diagnostic facts when conversing with their patients. However, with increasingly detailed diagnoses, a better informed public and improved methods of communication comes the responsibility of learning how to communicate more skillfully. The 21st century has also become more cognizant of patient rights and freedom of choice. This suggests that much of a health care professional's time with a patient will be spent explaining clinical medicine (Buckman, 1992); thus the need to communicate with others in a understandable and sensitive manner.

Improving the communication skills of delivering bad news is good professional practice for health care professionals. Patients' stress, anxiety, and depression are lessened when good communication takes place; thus, it is not surprising that patient satisfaction is closely linked to communication skills (Maguire & Pitceathly, 2002), as

opposed to technical skills (du Pre, 2017). It makes sense that such information be handled with care. This is not a one sided benefit. Good communication skills also impact a health provider's sense of professional satisfaction, which can result in less burnout (Maguire & Pitceathly, 2002).

Purpose

Due to the prevalence of chronic conditions, specifically cancer, occurring in Hawai'i including a high amount of breast cancer cases in Native Hawaiian women (American Cancer Society, 2016); and with little formal instruction for physicians on what is considered to be the difficult and daily task of communicating bad news (Buckman, 1992), there is a need to investigate the improvements to communication that can be made through physician training.

The purpose of my project was to learn about how health care providers can improve their communication skills when delivering bad news about a person's health. By hearing patients' perceptions of the effectiveness of communication of chronic disease diagnoses and comparing this to perspectives of skills training and real-life experiences of health care providers and nursing students, this research will inform health care providers of the areas that need to be improved relative to curriculum and training in Hawai'i. This research focuses on a patient-centeredness concept that emphasizes cultural responsivity in this specific health context. Because most physicians do not have a clear strategy on how to communicate upsetting news, this research provide methods to facilitate the bad news delivery process in a way that can be beneficial for health care professionals and communication teachers and professors who work with students in the health sciences.

Research Questions

The objective of this study was to analyze participants' experiences and perceptions when receiving a diagnosis of a chronic disease from their health care provider in order to identify ways to improve communication skills with health care professionals. Based on this objective, the research questions asked:

- What do individuals in Hawai'i experience when informed of a chronic disease diagnosis by a health care professional?
- What can we learn from these patient stories to inform culturally responsive communication approaches in health contexts?

Part of this analysis has involved gathering related information from health care professionals and nursing students regarding communication competencies in delivering bad news. Based on this inquiry, an additional research question asked:

- What do health care professionals and nursing students experience and learn when informing patients of a bad news diagnosis?

Definition of Bad News

For the purpose of this research project, bad news is “any news that drastically and negatively alters the patient’s view of her or his future” (Buckman, 1984, p. 1597). Buckman (1992) further elaborates that this definition implies that “the ‘badness’ of any bad news depends on what the patient already knows or suspects about the future” (p. 15). However, Buckman (1984) contends that how bad news is perceived will depend on the patients’ expectations at the time, how ill they actually feel, and whether they already know or suspect their illness. Ultimately, the impact of bad news depends on “the gap between the patient’s expectation (including his or her ambitions and plans) and the

medical reality of the situation” (Buckman, 1992, p. 15).

My Dad’s Story

“There is nothing more I can do. I did everything I could. He is not going to make it. How do you want to handle this?” The doctor looked at my mom asked, “Do you want to tell him or do you want me to tell him?” These words, spoken by my dad’s oncologist on the 7th floor of the Diamond Head wing of Queen’s Medical Center in the Fall of 2001, pierced through my mom’s heart while standing by dad’s bedside. With no prior warning of this decision, my mom was stunned and shocked from the suddenness of the news. This moment also hit her hard because for the first time, it became real that dad was not going to pull through from an illness. My mom decided to let the doctor break the news to my dad. He turned to my dad, repeated the bad news, and asked him, “where do you want to die? In the hospital or at home?” It was the most heart breaking words my mom ever heard and it still lingers with her till this day.

Although not stated explicitly by the doctor, my dad was going home for hospice care. Having been in the hospital for a year for treatment prior to that difficult conversation, it was not easy for my dad to have others take care of him. He fought the urge to let any illness side step his role as a husband and as a father. His values of hard work, determination, and being a provider were rooted in his childhood and learned throughout his adulthood.

Robert James Pickens, was born in 1938 in Wheeling, West Virginia. Due to my Bappap’s (grandpa) military duties as a Sergeant in the Army (my Tūtū was a seamstress), my dad lived in Japan but later returned home to West Virginia to finish his high school studies. Successful in school, he also soared in wrestling and in football. Despite his

recognition as a superior athlete, my dad recognized the importance of education by witnessing his parents' values of hard work and perseverance carried out by providing for the family. This is why he tried so hard in everything he did, especially in school.

Coming from an active military family, my dad decided to enlist in the Army and completed six years of service. While he was proud of serving others, he wanted to be the first ever in his family to graduate with a college degree. He began attending a junior college in Maryland, but decided to join his family in O'ahu (my Bappap's last station post was Fort Shafter in Honolulu) and attend University of Hawai'i at Mānoa (UHM), majoring in Psychology. While attending UHM, he once again excelled in wrestling and football. While going to school, my Tūtū helped my dad clean homes in the neighborhood to help pay for his college tuition of \$75 a semester. Her spirit helped my dad to push through the especially challenging courses—he did not want her to clean more homes.

A few years after graduating with his bachelor's degree, my dad met my mom at a bowling alley in Honolulu, O'ahu. They dated for six months before getting engaged. While they were engaged, my dad experienced a health crisis and had to get majority of his large and small intestines removed due to polyps. My parents married a year later and had three children (my brother, my sister, and I) over the years. After building the successful openings of several Firestone retail tire shops in O'ahu, my parents decided to move to Hilo, Hawai'i. My dad worked for many tire companies, including Goodyear, Hilo Petroleum, and Lex Brodies. I never knew the full story, but it seemed like almost every few years, my dad was selling truck and bus tires with other companies. I think it had to do with him being a top salesperson on the island and how companies offered

competitive wages. He even designed a tire tread for a commercial truck tire. He was known in the community as THE tire guy. As part of his practice, he personally delivered tires to companies who ordered them. This meant that he traveled island wide two or three times a week that resulted in endless paperwork in the evening.

By the end of the 90's decade however, the economy was slowing down and sales were not going well. In a position of sales, anxiety and stress fueled symptoms of a career burnout. But he plowed through these challenges because he did not want to let anyone down. Complicating the work stress were his health problems of type 2 diabetes, gout, and glaucoma. Gulping down prescription medications were part of his twice daily routine. From what I know, he did not question his doctor's orders as he was a highly compliant patient. You would never know he was in pain because he was not one to complain and simply carried on to the next task.

I did not know much about his work and health struggles because he did not often bring it up. Instead, he focused his communication on education and often asked what was learned in school for that day. It was not unusual for him to stay up late at night to help with homework. Attending college was not a choice—my siblings and I knew from an early age that obtaining higher education was a requirement. My mom later told me that my dad promised his mom (my Tūtū) that all of his children would graduate from college. You could say that he fulfilled his promise.

It was early fall of 2000 when I discovered that my dad was suffering from an illness. I needed to buy a few things from the grocery store and my dad, being my dad, offered to take me. We were in the parking lot of Safeway when he told to me that I was walking too fast. Surprised, I turned around and saw him breathing oddly. He had lost

weight in recent months, but with the amount of job stress, I thought it was a natural occurrence. That was my first recollection of seeing the signs of my dad's illness, and to tell you the truth, I was not paying attention to the details. After all, my dad seemed to recover or manage any illness, whatever it was. Breathing heavily, he mentioned to me that he needed to see the doctor again because the "asthma medicine" that the doctor prescribed was not working.

From what my mom told me, my dad went back to the doctor a couple of days after our shopping trip and was eventually prescribed a stronger asthma medicine. My dad really trusted his doctor as they knew each other for years. After all, he knew my dad's complicated health history. Weeks went by and his breathing problem was not improving. In fact, it was getting worse. Our family witnessed his breathing problem first hand when he tried to mow the lawn (he did not like to rest), but gave up after a few steps. The next day my dad went back to his doctor.

The doctor ordered my dad to Hilo Medical Center to conduct multiple exams, including a bone marrow test to determine if he was suffering from cancer. The tests showed that there was fluid between his heart and the sac that holds the heart. We were later told by a doctor that a healthy person has "20cc" worth of fluid between the heart and the pericardium sac; this fluid acts as a lubricant to keep the heart moving. My dad had over "2000cc" of stored fluid—enough to fill a half gallon of milk. It is a wonder that the sac did not burst immediately. A doctor drained out all of the fluid over the course of a few days, using a very long needle poked into my dad's stomach. The liquid around his heart kept building up after each draining, but was allowed to go home with a referral to see a cardiologist when his condition was stabilized.

The cardiologist in Hilo conducted multiple tests. While performing a sonogram the doctor said that he sees something, but could not make out what it was. My dad was ordered to fly to O'ahu later that day to see another cardiologist at Queen's Medical Center. After the appointment, while eating a quick lunch at home before getting his things together for the flight to O'ahu, the Hilo cardiologist called with bad news. I happened to be home at the time and watched in horror as my dad's face became nervous and concerned. While adjusting himself upright in his chair and scribbling words on a yellow tablet, he repeated what the doctor said, "You found a mass, I see." After hanging up, my dad sat in silence and said, "I have to tell your mother" while still holding the phone in his hand. I did not know what to say or do because I was in a state of shock—I just knew it was not positive by his facial expressions.

Through multiple exams by various doctors, my dad was officially diagnosed with heart cancer in November of 2001. Our family did not know anything more. Over the course of a couple of months, my father was in and out of treatment at Queens Medical Center. By March 2001, the cancer spread so rapidly that it was in his brain which caused him to suffer from severe headaches and paralyzed the right side of his throat. The doctor decided to surgically insert a tube in my dad's head so that chemotherapy could be inserted into the brain. This treatment was so harsh that my father suffered from seizures with each dose. Our family decided to stop with this treatment.

In June of 2001, my dad got the ok to leave the hospital (but stay in Honolulu) for a week to serve as a break. Although my dad was too weak and needed to stay in the hotel bed for most of the day, we were happy to be away from the hospital. He could barely walk and by that time, had lost a lot of weight. He also had a curly beard, which is

something that I never saw him with before. But this mini vacation was good for him because he smiled often, something he had not done in a long time.

Days into our stay, my dad went in for a routine blood test at Queen's Medical Center with my mom. They never came back to the hotel. My dad's cancer spread even more rapidly than before, and by this time, it had reached his liver. My mom called to tell us the news. He was immediately readmitted to Queen's Medical Center.

It was downhill from here. As the weeks went by, my dad lost almost all of his motor ability. He could barely move and even though we tried to exercise him by stretching, he could not turn himself in the hospital bed anymore. He was also not coherent for the most part and occasionally hallucinated. Although my dad and I did not make much conversation, he did mouth "I love you," enough to make out the words to each family member almost every day.

From my perspective, I noticed that my dad's doctors displayed a lack of team communication. One doctor said that we, as a family, needed to think about his quality of life. Another said that he could not tell us much and referred our questions to the lead oncologist. Another was opposed to holistic treatment; yet another suggested a few sessions of healing touch—a relaxation technique used to restore energy. The oncologist was against anything that was not empirically tested. To me, it appeared that his team of doctors did not communicate with each other.

Still, my mom still trusted the oncologist and felt that he was doing every he could for my dad. She appreciated his honesty and information sharing. She also liked that he took his time with my dad as it did not seem like he was rushing to the next patient. Our family found most of the nurses to be supportive and caring. The answered

our questions, checked in often, and showed compassion. One nurse in particular gave my mom a hug at the end of every shift. She became a shoulder for my mom to cry on.

In August 2001, I began graduate school at the University of Hawai`i at Mānoa, majoring in Speech (now Communicology). I was also a graduate teaching assistant (TA) at the time, teaching three sections of public speaking to undergraduate students. My first semester at graduate school was no doubt an overwhelming experience. Due to my responsibilities as a student and as a TA, most of my time was spent on campus. I thought about quitting school numerous times because there was an enormous amount of pressure to do well, but I also felt that it was the wrong time to be in school. I thought about how my dad wanted me to succeed; I thought about his educational talks at the dinner table; I thought about how I would disappoint him if I did not push forward, like how he did while going to college. At the hospital, his face would light up every time I told him about what I learned that day. Those moments were like nothing changed from childhood; we still communicated about education.

My mom was able to sleep in my dad's private hospital room almost every night. Occasionally she needed a break from the hospital bunker as it was not the most comfortable place to sleep. My turn to sleepover was the night of September 10, 2001. I remember the next morning so well. I woke up with the TV blasting NBC news and my dad's eyes glued to the television set. As the replay kept looping of the Twin Towers collapsing, I heard my dad say, "That's terrible." I sprung up from the roller bed and looked at him. He peeked at me through the corner of his eyes and very slowly moved his head from side to side. Even though he was not coherent and did not speak much, he knew what was going on. With my heart racing with excitement, all I wanted to do was

call my mom and tell her that dad said something out loud. While it was an amazing moment for us as a family, our entire country was crying.

September 11 was not the only day I remember. On September 18, my parents celebrated their 30th wedding anniversary. We ate ribs from Toni Roma's and indulged in a two layer chocolate cake. It was nice to see him enjoy a piece of the rib, even if it was just a bite. That was a special moment because my dad had been placed on diet restrictions for a good part of the year, so this felt like a real celebration. On September 26, we celebrated his 63rd birthday. We ordered pizza and picked up a carrot cake, his favorite dessert. Our family's favorite nurse decorated the room with fake flowers and ribbons. She also handmade a huge birthday card, signed by each nurse on the floor. That nurse took special care of him and called him her "baby blues" in honor of his bright blue eyes.

In the beginning of October 2001, my mom told us that my dad was being discharged from the hospital and flying back home to Hilo. She mom was able to transport my dad and set up proper home care with specialized nurses. My sister and I decided to fly home from O`ahu every weekend.

That weekend my mom told us the reason my dad came home to Hilo: to die. When the oncologist posed the question of "where do you want to die," my parents, with the oncologist encouragement, decided that it was best to go home to Hilo. Once I heard the news, I went into a state of shock and for a period of time, I did not know where I was. I was crying so much, I vomited. It was only until my mom told me to grab his hand and look into his eyes that I could calm down. I remember him looking at me and smiling ear to ear. He knew his fate, and yet comforted me.

My mom waited until the weekend to tell us the news because she wanted all of us to be in the comfort and security of our family home. She encouraged us to continue with our studies and work hard towards our education like how my dad wanted us to. I know that for myself, I would have given up on school and moved back to Hilo. I knew my dad would be disappointed if I had done that.

The next weekend, on October 26, 2001, my sister and I flew home to Hilo. We were eager to see how he was doing and walked into our family home with anticipation. As we took our steps down the long hallway, we immediately caught our mom's facial expression and pale complexion. I immediately knew what was going on and collapsed toward the end of the hallway: He died about an hour prior to us coming home. My aunt claimed that my dad did not "leave" his body until he saw my sister and me.

Two weeks later, a funeral was held in Hilo. Many people were there, including my dad's general practitioner who misdiagnosed him as having asthma. As a family, we were shocked that he showed up. He did not say much; just that he wished us well. Years later, my mom told me that she never forgot that moment because she was not expecting him to deliver a card, much less say anything to us.

When I returned to school, I disclosed to my advisor at UH Mānoa about our family's experience with my dad's health care providers' communication. Why was he told bad news over the phone? Why was there no support in the room available for my mom as she heard the final decision? My advisor recommended health communication as a field of study and shared with me a few articles to read. Inspired, I began to specifically look at how my family was told of the bad news and the dynamics of that experience. My

family didn't even know the name of the cancer, but maybe we did not play an active role in retrieving that information either.

Through my own research via conversations with my mom and my dad's favorite nurse, I learned that my dad suffered from primary cardiac sarcoma, which happened to be malignant (as opposed to benign, or noncancerous). According to John Hopkins Medicine website (2016), tumors are considered to be either primary or secondary. A primary cardiac tumor is one that starts in the heart, while a secondary cardiac tumor starts somewhere else in the body and then spreads to the heart. Primary and secondary cardiac sarcomas are the least researched subjects in oncology (Lam, Dickens, & Chan, 1993). Primary cardiac sarcomas have an incident rate of .0017 to .019%; hence, it is a very rare and aggressive form of cancer (Devbhandari, Meraj, Jones, Kadir, & Bridgewater, 2007).

The most common type of cardiac sarcoma is angiosarcoma, which usually begins in the right atrium of the heart (John Hopkins Medicine website, 2016). Cardiac angiosarcomas can cause increased fluid in the pericardial sac, the thin covering that surrounds the heart because the tumor is blocking proper blood flow (University of Rochester Medical Center website, 2016). If enough fluid accumulates within the sac, the heart's ability to pump blood is affected (John Hopkins Medicine website, 2016). This is what happened to my dad. The tumor was growing so rapidly that it affected his blood flow; thus, fluid was misdirected and accumulated between his heart and the pericardial sac. That explains why he had dyspnea—or difficulty breathing. The fluid was squeezing and compressing his heart. Besides difficulty in breathing, other symptoms may include hemoptysis (coughing up blood), chest pain, heart rhythm problems, and upper facial

congestion, all of which are related to the location of the tumor on the heart. Other signs of cardiac sarcoma not related to the tumor location may include fever, weight loss, night sweats, and feeling fatigued (John Hopkins Medicine website, 2016). However, symptoms occur only when the tumor is relatively advanced (Hamidi, Moody, Weigel, & Kozak, 2010).

Research has shown that the average survival rate is approximately six months (Hamidi, et al., 2010). Therefore, primary cardiac sarcomas have poor prognosis (Putnam, Sweeney, Lanza, Frazier, & Colley, 1991). My dad battled his cancer for almost a year with the help of chemotherapy and radiation before passing on, which says a lot about how determined and aggressive the doctors' were about the treatment. Research has also shown that surgery is the best form of treatment for cardiac sarcoma as it is the only mode of therapy that shows benefits. However, due to the rarity and lack of case studies of primary cardiac sarcomas, there is no current uniform approach for treatment (Devbhandari et al., 2007; Hamidi, et al., 2010; Putnam et al., 1991). In fact, tiny pieces of cardiac sarcoma may break off and travel through the bloodstream to other parts of the body (University of Rochester Medical Center website, 2016). This may cause improper blood flow to an organ or body part, causing pain and damage to organ(s). Over the course of the year, particularly in 2001, the cancer had spread to other parts of my dad's body, including his throat, brain, and liver. This made treatment especially more difficult.

The effects of my dad's health journey have been life changing. For some time after, my mom could not stomach walking into another doctor's office or smell and feel a hospital's air conditioning. It made sense that hospitals, especially, do not bring good memories for her. With time, she recognized that she needed to see a doctor for certain

ailments that she was experiencing, but she would not go to any appointment unless a family member was present with her for support.

Not all outcomes were negative. My dad's special nurse continued to interact via email and phone with my mom following his passing. Their friendship continues to this day as they have an occasional lunch date whenever visiting each other's respective island. This relationship suggests that when good communication practices are in place in this specific context, it can have a long-term positive effect. In addition, my dad's journey lead me to the field of health communication and education.

What I observed while "living" in the hospital changed my perspective and direction in my educational journey and in life. Over the course of my dad's yearlong treatment, I noticed communication patterns and discrepancies between the doctors and nurses. As mentioned earlier, when I mentioned this to my graduate school mentor, she opened my eyes to the field of health communication.

Since I did not receive any introduction of this field during my undergraduate studies, I was completely new to this area of study. I started from scratch. I read articles from academic journals, watched news stories on TV, and talked with family members who were going through their own health journeys. From there, I focused on health communication as the direction for my Master's thesis. After graduating and then working as an instructor at the University of Hawai'i at Hilo (UHH) for a couple of years, I felt the tug of doing more to better serve the student population who are pursuing health careers. Current topics in health issues must be heard, celebrated, and challenged. With an absence of an introductory health communication course, I felt a responsibility to create one. This being my driving force, I submitted a proposal for a new course in 2006

titled, *Communication 241: Health, Culture and Diversity*. This course was approved by the Curriculum Review Committee and implemented in the fall 2007 semester.

To provide a brief background of COM 241, below is the course description as stated in the current UHH online course catalog:

Overview of the study of health communication. Aimed to provide exposure to concepts and principles in the field, focusing on advocacy and individual awareness in current events. Topics include the dynamics shared between health care providers and patients, the role of mass media, promotion of public health campaigns and culturally diverse approaches to health care. (University of Hawai'i at Hilo, 2017).

Since its creation, I have had the honor of introducing health communication to a variety of UHH students enrolled in diverse majors including Communication, Psychology, Sociology, Kinesiology and Exercise Science, Pre-Nursing, Pre-Pharmacy, Biology and students who have verbally committed to a career in medicine. Most of my students are interested in pursuing a career in health where they are the professional provider, whether it is a physician, nurse, physical therapist, or psychologist. While many of my students appear excited about the educational journey and the humanitarian value of being a health care provider, discussions surrounding the perspectives of patient experiences, either from themselves or from family members, are key points of interest throughout the semester. Students voluntarily share their stories of health and healing, including the emotional rollercoaster that one experiences and how culture impacts the way they receive and utilize health care. Based on their experience, students often share their perspectives on what professional providers could do better from a communication

standpoint. By the end of the course, students have mentioned (verbally and in course evaluations) that they come away with a better understanding of what it means to communicate with or as a health care professional, especially in a cultural context. In addition, by becoming more aware of the various factors that affect the way health professionals and patients communicate, students are then able to apply that knowledge to strengthen the various personal and public arenas they may be a part of. I believe that a large part of their understanding comes from critically reflecting on personal experience and learning from each other in class discussions.

This study gives further evidence that a person's story about their health journey is incredibly valuable and worth sharing. We all benefit from learning from one another, yet voices are not always heard. My current work and research is reflected in my dad's story and I hope to continue the conversation surrounding difficult conversations and patient experiences.

Towards this effort, three questions guide this research project. Understanding the experiences of a chronic disease diagnosis in Hawai'i, learning from their stories to inform culturally responsive care, and by acquiring the experiences and educational training of health care professionals and nursing students, this research seeks to provide information that could benefit current and future health educators and students.

Chapter Two

Literature Review

In this chapter, I provide a review of the literature about delivering bad news. I begin with patient perspectives, focusing on their experiences and communication preferences in an effort to address what individuals in Hawai'i experience when informed of a bad news diagnosis. Then, I focus on health care professionals, specifically with physicians and nurses, and share their experiences and challenges of delivering bad news. To explore about what is learned through instruction, I also provide a sampling of available guidelines for health care professionals that may be used in skills training. The last part of this chapter examines the role of culture in delivering and receiving bad news to better understand approaches to culturally responsive care.

Patients' Perspectives

Patient experiences. In discussions of how patients receive health news from their caregivers, one controversial issue has been the range of effect this has on the patient experience. Schaepe (2011) argues that patients' experience of the medical system prior to hearing the news, played a role in the way the news was psychologically processed by the patient. In this multi-year study from 2007-2010 which examined the medical and psycho-social experiences of blood and bone cancer patients' and their caregivers before and over a one year period after receiving hematopoietic stem cell transplant (HSCT), three categories emerged: *bad news by a good process*; *good news by a bad process*; *bad news following a bad process*.

In *bad news by a good process*, patients and caregivers described the efficiency and effective interdepartmental team communication that resulted in learning about the

diagnosis quickly. For example, one patient described an experience where, through coordinated care of many doctors, rapid communication after cancer was determined to be the cause of the kidney failure. Within a matter of hours after receiving the biopsy results, the patient was receiving the first round of chemotherapy. Schaepe (2011) notes that the organizational support from a range of specialists resulted in less trauma and negative impact for the patient.

Good news by a bad process was experienced by a patient who was told that the cancer returned when in fact the doctor read the X-ray incorrectly. As a result, the family felt re-traumatized instead of feeling relieved that the cancer did not return (Schaepe, 2011).

Bad news following a bad process was experienced by a patient who learned of the cancer diagnoses from a physician who was not familiar with the patient. The physician, who was staffed at the hospital, inadvertently revealed to the patient the type of cancer the patient had, before the patient heard from his primary physician (Schaepe, 2011). The family was very upset, although the doctor did later apologize. These stories showcase how the communication process can influence patients' feelings and emotions with a diagnosis is shared.

Schaepe (2011) contends that patients and caregivers (if present) almost always could recall verbatim one or two specific phrases that the doctor said while disclosing the diagnosis beyond the informational content of the message. They latched onto certain words that were positive or on the "bright side," including one patient who learned from the doctor that their cancer was "very treatable" (Schaepe, 2011).

Research on patient experience has also determined that patients may interpret the bad news encounter differently than their providers. Salandar (2002) conducted a study that examined the written narratives from 187 newly diagnosed cancer patients. Salandar (2002) contends that participants often describe their experience as a process, from the symptom detection to diagnosis and treatment. Thus, the experience is not reduced to the moment of diagnosis. This is different from physician perspectives which may focus on how to adequately provide information to the patient specifically when bad news is communicated (Salandar, 2002).

Salandar's study supports Tobin and Begley's (2008) research where the phenomenological exploration of the lived experience of receiving a cancer diagnosis was investigated. Ten participants from the Republic of Ireland were interviewed to understand their story of a cancer diagnosis. The first finding was the disturbance of the everyday world where "the participants move from a place of 'knowing' within their everyday life to a place of needing to know" (Tobin & Begley, 2008, p. E34). In other words, the diagnosis was a disturbance of their everyday living that challenged their sense of normalcy. Second, participants struggled with life after the diagnosis as they attempted to redefine their everyday world and living. Finally, participants may live within a fear of the future, one in which they realize that the cancer may later return. Thus, patients may interpret their diagnosis as a process: before, during and after the diagnosis.

The interpretation of a patient's health care experience may stem from their culture. In their study, Braun, Mokuau, Hunt, Kaanoi, and Gotay (2002) conducted multiple focus group sessions where 45 Native Hawaiian cancer survivors were asked

about their cancer diagnosis. Their research found that some of the participants were active sought health care and had their cancer discovered through regular screening. Other participants did not want to go to the doctor's office because they were reluctant to interact with a Westernized health care system (Braun et al., 2002). Based on their experience and of their family's experience of cancer, many participants already had a fatalistic attitude about the cancer and did not communicate about it with their family members (Braun et al., 2002). This finding is similar to that of Elde's (2006) study that explored Native Hawaiian women's experiences of surviving breast cancer. Participants of Elde's (2006) research hid their diagnosis from others, particularly family members, as much as they could. In all, both studies suggest that it is advantageous to create a cancer support group for Native Hawaiians to encourage dialogue and open discussion.

Patient preferences. When it comes to the topic of patient preferences, most health care professionals agree that as a previous or current patient, we have strong feelings of what we like and do not like about patient care, including how bad news should be communicated.

Information. With such a range of experience that patients have in receiving bad news, it is obvious that in the giving of bad news, patients like to be well informed. In a classic study assessing patients' preferences by Parker et al. (2001), 351 patients with a variety of cancers completed a survey assessing the manner in which they would like to be told of their cancer diagnosis. The highest rated preference was content (what and how much information was told), followed by facilitation (setting) and support (providing emotional support during the news). It was also determined that female participants who

had high education levels wanted more medical and treatment information regarding their cancer (Parker et al., 2001).

Other studies have shown similar results. Brown et al. (2011) conducted a study examining the communication preferences of recently diagnosed oncology patients at the Leicester Royal Infirmary, United Kingdom. Brown et al. (2011) determined that patients were able to identify preferences regarding how they would like the news delivered. Content of the message was described as most important, then facilitative (such as the environment) and support. However, as the patient's age increased, the importance placed on all three issues of content, facilitation and support decreased. Patients who were unhappy with their experience of the bad news consultation rated support and facilitation higher than those who were happy with their experience (Brown et al., 2011). In the same study, patients also wanted to know their prognosis and felt this information should be conveyed in the delivery of the news (Brown et al., 2011).

It appears that patients want all available information, including prognosis and treatment options. In investigating patient preferences for communication practices, Schofield and colleagues (2001) led a study examining the perspectives from Australian melanoma patients. In terms of information sharing, patients wanted to know "everything," including "how their cancer would affect their life expectancy" (Schofield et al., 2001, p. 367). Patients also wanted to know "everything" about treatment options and welcomed supplementary written information targeted to their cancer (Schofield et al., 2001, p. 367).

Similarly, Fujimori and colleagues (2007) examined patient preferences of the disclosure of bad news at National Cancer Center Hospital East in Japan which treats

breast, digestive, head and neck, and lung cancers. In their study consisting of 529 patients who answered a questionnaire, it was found that physicians should deliver both positive and negative information pertaining to the disease and treatment (Fujimori et al., 2007). Positive information included providing the patient with a treatment plan and instructing what the patient could hope for; negative information included the risks and side effects that could result from the treatment (Fujimori et al., 2007). These studies suggest that when physicians disclose bad news, one of the most important preferences of a patient is to receive all pertinent information. Patients did not like it when the physician was vague (Fujimori et al., 2007). On a similar note, patients preferred a speedy turnaround of exam results (Butow et al., 1996), which supports the idea that patients want as much information as possible and as quickly as possible.

Tattersall, Griffin, and Dunn (1994) explored patients' preferences for communication aids following an appointment with the oncologist. The study design focused on two aids, an audiotape of the entire consultation or a letter consisting of tailored, informative points provided by the physician. From a sample size of 176 patients, it was determined that patients wanted information pertaining to their illness, whether it was good or bad news, and had a preference for audiotapes to letters. This study suggests that providing additional information to the patient in between medical visits is potentially beneficial for the patient and their families. If support materials are not shared, patients will sometimes seek out information for a variety of sources on their own through book, articles, the internet, family, friends, relatives and community events (Braun et al., 2002). These findings demonstrate patients have a strong desire for learning more about their illness. In contrast, Roberts, Cox, Reintgen, Baile, and Gibertini (1994)

study that found that newly diagnosed breast cancer patients' rated the importance of a caring provider higher than that of receiving information. This could be because the 25 participants were newly diagnosed; thus, the impact was fresh and there was greater need for support and comfort rather than information.

Emotional support. Along with providing content, patients also preferred to have emotional support from their physician during the delivery of the bad news. Martins and Carvalho (2013) showed four different doctor and patient interaction scenarios on videotape to 72 outpatients in the endocrinology clinic of the Portuguese Institute of Oncology. Each video depicted a different scenario portrayed by a female physician disclosing the bad news diagnosis to a female patient: *The emotionally burdened expert* (touches the patient, feels sad); *the empathic professional* (keeps eye contact, shows empathy); *the distanced expert* (avoids showing or discussing emotions); and *the rough and ready expert* (tough, ignores the patient's emotions). The participants then selected the model they preferred, answered a questionnaire, and finally interviewed about their choices. Results indicate that the patients in this study preferred *the empathic professional* over all of the other styles and expressed a strong dislike for *the rough and ready expert*. Interestingly, more than 60% of participants stated that they received the bad news diagnosis in a way different from what they would have preferred and in fact, the very model they dislike—*the rough and ready expert*—was experienced by 21% of the participants (Martins & Carvalho, 2013).

In this same study, it was determined that age and education were factors in determining preferences. Younger and more educated patients preferred *the empathic professional* while older and less educated patients preferred *the emotionally burdened*

expert (Martins & Carvalho, 2013). This finding echoes Parker et al.'s (2001) study in which female patients' preferred supportive behaviors from their physician. *The empathic professional* was also a popular choice to those that were experiencing cancer at the time of the study.

Findings from Martins and Carvalho's (2013) study is similar to another study to determine how different physician communication styles affect patient satisfaction (Mast, Kindlimann, & Langewitz, 2005). Based on the work of Brewin (1991), Mast and colleagues (2005) characterized three communication styles of physicians: *disease-centered* (blunt and insensitive); *emotion-centered* (overly empathizes and sympathizes); and *patient-centered* (understanding and positive, displays empathy).

Each style was depicted in three separate video clips, featuring a male physician giving the bad news of a breast cancer diagnosis to a female patient. One of the three scenarios was randomly shown to 159 female students of all majors from the University of Zurich. Of the three communication styles, the patient-centered physician ranked highest for patient satisfaction. These studies suggest that patients want a physician who is empathic and sensitive when giving the bad news.

Health Care Professionals Perspectives

Physician Experiences. In discussions of how the delivery of bad news impacts a physician, one controversial issue has been the range of experiences for the physician giving the diagnosis. Ptacek, Fries, Eberhardt, and Ptacek (1999) sought to gain a better understanding of the process of communicating bad news. In a survey of 38 physicians from three clinics, it was determined that they did not always have time to prepare statements. In trauma or emergency situations, the physician only had 3-5 minutes to

think and then deliver the devastating news to the patient. As such, it was difficult to tailor the delivery to each patient, especially when the physician had minimal or no contact with the patient prior to the diagnosis.

Not surprisingly, stress appears to be a factor for physicians during the delivery of bad news. Shaw, Brown, and Dunn (2015) investigated the relationship between a physician's delivery style of communicating bad news and their physiological stress during simulated consultations of bad news. Thirty-one participating doctors were monitored and recorded for their heart rate (HR) and skin conductance (SC). Delivery style was characterized as either blunt (doctors delivering news within the first 30 seconds without providing context), forecasting (provided warning shots, followed by detailed communication of illness) or stalling (provided information, but delayed the actual news delivery or avoided being explicit of the bad news). As indicated by increased HR and SC levels, doctors felt stressed when the patients did not know of the bad news and had to inform the patients.

It also appears that physicians tend to experience strong physical and emotional reactions during the time of cancer diagnosis. Shaw, Brown, Hennrich, and Dunn (2013) explored the perceptions of 28 junior and senior physicians who recalled giving a bad news diagnosis in interviews. The intent of the study was to identify the physical and emotional experiences associated with this stressful task. This study found that the physicians did experience physical (sweating, heart palpitations) and emotional (feeling drained) stress symptoms during the task. Interestingly, the physicians preferred to call this task unpleasant, uncomfortable, painful or rough, with feelings of dread, nervousness and anxiety producing, as opposed to a stressful experience. That view may have

contributed to how physicians in this study felt that communicating such news is a part of being a doctor; thus it is a natural, expected occurrence. Focusing on emotional reactions, Shaw et al (2013) results are similar to that of Mystakidou, Liossi, Vlachos, and Papdimitriou's (1996) findings of physicians reporting feeling sad and a high amount of anxiety.

The research on the years of experience in relation to physician's comfort level and coping strategies during the bad news delivery is mixed. In examining the perceived stress levels of junior and senior doctors were similar, which suggests that years of medical experience did not factor into lessening the emotional intensity of the breaking bad news task (Shaw et al., 2013). This finding is in contrast to a mixed method study comparing practicing pediatric residents, fellows, and attending physicians at a quaternary care center, where it was determined that the comfort level of the physician was found to increase significantly by years of training (Orgel, McCarter, & Jacobs, 2010). Additionally, comfort level was more related to the years of training a physician receives than to their chosen specialty (Orgel et al., 2010). However, senior doctors did report using more problem focused coping strategies, which are aimed at controlling or changing the stressful situation, including limiting the breaking bad news encounters and informing themselves of necessary clinical information (understood illness, understood treatment options) before delivering the news to the patient. Years of experience and the perceived stress experienced could be the result of the location, thus culture, of where the study took place. For example, in a survey conducted with 458 physicians from the Qassim Region of Saudi Arabia, Al-Mohaimed, and Sharaf (2013), explored the perspectives and practices from physicians when delivering bad news. The survey asked

to rate their opinion of good communication skills based on the SPIKES model of delivering bad news (Baile et al., 2000). Senior physicians (those with high qualifications) had lower communication competency skills of giving bad news compared to junior physicians. Doctors who had difficulty delivering bad news may struggle with their own negative feelings about the transaction, not knowing what to say, anticipating the right time to communicate such news, and self-doubting their ability to answer questions that may arise (Gauthier, 2008; Hancock et al., 2007), all of which may heighten stress, despite years of clinical experience.

Situational factors may cause stress for a physician. In a two part study, Ptacek and McIntosh (2009) sought to examine the factors that influence how difficult it is to break bad news to patients. In the first part of the study, 94 unique statements given from 32 physicians were grouped by categories which included physician factors, patient factors, institutional factors, illness factors, relationship factors, and mishap factors. In the second part of the study, 115 physicians rated how stressful each of the statements in a category were. Results showed that physicians rated mishaps factors, such as when the patient dies due to medical error and when their care contributed to a poor outcome for the patient, as most stressful.

Although an uncomfortable encounter, physicians report that they were effective in transmitting the news in a way that reduced both their own stress and the stress of the receiver (Ptacek et al., 1999). This is in contrast to Shaw et al.'s (2015) research where doctor's experienced heightened HR and SC when they were able to assist the family in dealing with the immediate consequences of the bad news in the post bad news phase of

the interaction. In some cases, the stress experienced by the physician lasted beyond delivering the bad news itself.

Ptacek, Ptacek, and Ellison (2001) aimed to provide a description of the behavioral, cognitive, and emotional responses that are typical for physicians to experience while breaking bad news and identifying factors that distinguish transactions that went well from ones that went poorly. Results showed that while physicians experienced moderate stress during the delivering, the stress lasted days after communicating the news to the patient. This was particularly evident in interactions that went poorly and there was not an established relationship between the patient and doctor. Still, delivering bad news can be considered an encounter that doctors do not like to do, but have to do. Although the majority of participants in Al-Mohaimed and Sharaf 's (2013), research did not avoid telling their patient the bad news, most would rather communicate that type of information to the patient's family member than to a patient itself. This finding speaks to the difficulty of such a task.

Why is it difficult? Buckman (1992) posits that every physician dislikes, and even fears, the act of breaking bad news and describes several possibilities as to why. First, doctors do not want to be blamed. Further, doctors find it a relief when patients mention that they already knew it was cancer. Second, doctors fear the unknown or untaught. Due to limited training in medical schools, doctors do not have much background in talking to dying patients (Ptacek & McIntosh, 2009; Buckman, 1984). Buckman (1984) insists that experience and training helps to build communication skills for these situations. Third, not knowing how to deal with this type of specialized communication can make a doctor feel inadequate and unleash a negative reaction from

the patient. For example, if a patient cries, doctors may feel that they did not take the proper steps to avert that emotion. Furthermore, physicians may find it difficult to give bad news when they believe they are lacking the appropriate and necessary resources, including time and adequate space (Ptacek & McIntosh, 2009). Fourth, doctors find it difficult to be sensitive and compassionate when they are taught in medical school to be professional, calm and suppress panic. Fifth, junior doctors in particular feel intimidated when they do not know all of the answers. Saying “I don’t know” may rattle their self-confidence. Sixth, doctors may have a personal fear of illness and death and may keep at a distance to protect themselves. The bad news situation may “hit close to home,” reminding physicians of their own mortality or of the possibility of a similar fate for a family member (Ptacek & McIntosh, 2009). If the patient and physician shared a close relationship, the news may result in an end to that friendship. In addition, some doctors are inclined to believe that illness cannot happen to them. In doing so, they promote the illusion of invulnerability. Overall, most health care providers feel that they are unskilled to handle such a daunting task.

Nursing Experiences. Nurses participate in an intricate part of the medical care in caring for a patient, but their role in breaking bad news has not been adequately described in the literature (Abbaszadeh, et al., 2014; Dewar, 2000; Warnock, Tod, Foster, & Soreny, 2010). Yet, it is evident that opportunities to learn from a variety of health professionals is missed when the focus is placed solely on the doctor in this type of transaction (Dewar, 2000; Warnock et al., 2010). As stated previously, Salandar (2002) and Tobin and Begley (2008) argued that breaking bad news could be perceived as a process due to the communication occurring with various health care professionals

before, during, and after the moment of diagnosis. As such, breaking bad news can be viewed as a collective effort of various health providers (Fallowfield & Jenkins, 2004).

A goal of nursing is to provide information and support for the patient, including responding to questions from family members (Warnock, 2014). However, difficult conversations, such as delivering bad news, can be the beginning of a relationship that may affect the future coping abilities of patients and families (Little & Bolick, 2013). For example, Dewar (2000) examined the role of a nurse when communicating bad news to patients in a spinal injuries unit. Derived from interviews conducted with 22 registered nurses practicing in Canada, Dewar's (2000) research highlighted that nurses viewed their role in various ways. One way is that of a support and educational liaison for patients and their families. Many felt that it was the responsibility of the physician to disclose the bad news. Still, patients often turned to the nurse for clarifying what the doctor said. This most likely occurred because the patient did not understand complex information that was given by the doctor. As such, nurses may become the bearer of bad news. In addition, nurses were often tasked to answer unpredictable questions from patients and family members, leaving them to think quickly. This leaves nurses in awkward situations, such as when a patient asked, "Am I going to walk again?" (Dewar, 2000).

Why is it difficult? Nurses face many barriers when having to break bad news. Nurses frequently report not feeling prepared, not having enough time to break the news, and having patients who did not want to know the diagnosis (Warnock, et al., 2010). Given this, it is not surprising that nurses often feel like a failure during these difficult discussions. Knowing that the content of the information is difficult to hear and because

they cannot change the outcome of such news for their patient, nurses may feel inadequate because they did not or could not “fix things” for their patient (Stayt, 2007). Still, nurses report that the relationship that developed with the patient strengthened because they were involved in this process of delivering bad news (Warnock et al., 2010).

Part of what makes these interactions stressful is that many providers feel that when it comes to communication issues, they are not adequately trained (Ptacek & McIntosh, 2009). It appears that communication skill training in this area is key. Nursing students often describe communicating bad news to be more challenging in the clinical setting than anticipated during practice sessions (Warnock, 2014). Little and Bolick (2013) argue that proper preparation of communicating bad news, for both pre-licensure and graduate nursing students, better prepares them for future clinical conversations and encourages incorporating role playing scenarios and group discussions using SPIKES (What is this?) developed by Baile and colleagues (2000). Therefore, describing their training and educational experiences of their role in communicating bad news is imperative for health communication interactions.

Guidelines for Delivering Bad News

In discussions of how to best communicate bad news to a patient, one controversial issue is the development of recommended guidelines by health care professionals. Much research on the best practices of how to break bad news have been based on extensive clinical experience and the expert opinion of practicing medical doctors with little empirical foundation (Baile et al., 2000; Ptacek & Eberhardt, 1996; see Brewin, 1991). The research also suggests that guidelines for this area were not only

developed by health care professionals, but also refined by health care providers (see Girgis & Sanson-Fisher, 1998). Additional guidelines for delivering bad news have been derived from patient families in an effort to be recipient-specific (see Garwick, Patterson, Bennett, & Blum, 1995).

It is noted that physicians may develop a particular style of delivery when communicating bad news. Thurstan B. Brewin, a noted medical doctor of radiotherapy and oncology from the UK, focused much of his academic research describing the relationships between patients and their relatives and doctors, patient sensitivity, medical ethics, and clinical management. In his research, Brewin (1991) discusses three ways physicians give bad news to their patients. The first is the blunt, unfeeling way. Physicians who give the news in this manner say they do so because the patient will be upset no matter how the information is communicated. The second way is gravely and solemnly, with little positive support or encouragement. Physicians who give bad news in this manner do not want to give false hope to the patients. Physicians do not want to raise any hope of the patient getting physically better because chances of that happening are very slim. Brewin (1991) suggests the best way a physician gives bad news is through positive thinking, reassurance, and planning for the immediate future. A physician encourages reassuring thoughts while preparing future treatment(s) or other options that are comfortable to all parties involved.

One of the most popular guidelines designed to help physicians with the delivering of bad news is called SPIKES (Baile et al., 2000). In their research, Baile and colleagues (2000) argued for a need for increased clinician skill in the delivering of bad news. This need was illustrated when they conducted an informal survey at the Annual

Meeting of the American Society of Clinical Oncology in 1998 (Baile et al., 2000). The nature of this symposium concentrated on doctor-patient relationships in oncology. Five hundred (of the 700) persons attending the symposium answered questions that were poised from the projector screen. That is, the participants took part in the survey in “real time.” This informal survey asked participants about their experiences in breaking bad news. The data suggested that the most difficult part of breaking bad news was being honest, but not taking away hope from the patient (Baile et al., 2000). Baile and colleagues (2000) argue that the task of breaking bad news can be improved by approaching it as a step process that is grounded in communication and counseling principles. SPIKES is a six step protocol that embraces those principles.

SPIKES is an acronym for the stages of communication in this setting, including *setting, perception, invitation, knowledge, empathy, and summary* (Baile et al., 2000). The first step is setting up the interview. In this step, physicians must arrange privacy, such as closing curtains in the room; sitting down with the patient because it is a nonverbal sign of not rushing; connecting with the patient, including establishing and maintaining eye contact, and touching the patient in a way that provides support. The second step is the assessing the patient’s perception. Baile and colleagues (2000) claim that in order to correct any misinformation, physicians must ask the patient what they have been told about their medical situation. This helps the physician determine a picture of what the patient already knows and does not know. The third step is obtaining the patient’s invitation. Most research claims that patients want to know their diagnosis. According to this step, physicians could ask the patient how they would like to have the information from the test results delivered (Baile et al., 2000). This suggestion supports

Brown et al.'s (2011) study where majority (44.5%) of patients wanted to be involved in the decision making process. By asking questions such as "How would you like me to give the information of the test results?" provides the patient an opportunity to be active and engaged in this process. This step could be determined in earlier conversations, such as when the tests are actually taken and not when the results actually come in. This could guide the physician to prepare early and practice intrapersonal communication prior to the divulging of the results. The fourth step is giving knowledge and information to the patient. In this step, Baile et al. (2000) say that a warning statement, such as "The tests did not come back as expected" helps to lessen the impact. Baile et al. (2000) also advises physicians to adjust the vocabulary to the patient's level so that the patient can clearly understand what the physician is saying. Addressing the patient's emotions is the fifth step. Because patients' emotional reactions can vary, it is important that physicians first observe the emotion to make sure that the bad news was the reason for the reaction. Physicians should also try to make a connecting statement, such as "I know this wasn't what you wanted to hear" (Baile et al., 2000, p. 309). The sixth and final step in the SPIKES guideline is the strategy and summary. In this step, physicians must make sure that patients are ready to discuss the treatment plans. In fact, patients who have a clear plan of action are less likely to feel anxious and uncertain (Baile et al., 2000).

Other guidelines for breaking bad news have been developed and refined by health care providers. Girgis and Sanson-Fisher (1998) present a summarized list of key principals and specific steps for breaking bad news that was initially developed by the New South Wales Cancer Council and the Post Graduate Medical Council in Australia. These guidelines were later revised based on feedback from health care providers and

communication skills trainers in Australian medical schools. These findings led to the most essential steps in breaking bad news to medical patients. First, it is recommended that doctors give the news in a quiet, private place. This includes not sharing the news on a phone call; rather, find a separate room in the hospital or close the curtains around the patient's bed. This is not only to ensure privacy, but also to help the patient feel more comfortable (Girgis & Sanson-Fisher, 1998). Second, doctors should allow enough uninterrupted time in initial meeting. One way to avoid interruptions is to silence beepers and cell phones prior to communicating the diagnosis (Girgis & Sanson-Fisher, 1998) or to handle any incoming communication prior to communicating the diagnosis. Third, doctors should assess patient's understanding and emotional status. The patient may already have a high or low level state of awareness about their bad diagnosis and prognosis. Thus, once assessed, this perspective may help to determine where the conversation could start (Girgis & Sanson-Fisher, 1998). Fourth, to minimize miscommunication, doctors should provide information simply and honestly. That is, doctors are encouraged to avoid using jargon and use simple language that is easy for a patient to understand. Further, patients have the legal and moral right to accurate information; this becomes more apparent in instances where informed consent is required (Girgis & Sanson-Fisher, 1998). Fifth, doctors should encourage patients to express their feelings. A patient's immediate reaction may be one that is negative, such as disbelief and anger—this is natural (Girgis & Sanson-Fisher, 1998). Let the patient know that such emotions are welcomed. Sixth, doctors should respond to patients' feelings with empathy. Using appropriate touch to express warmth and sensitivity creates a supportive climate (Girgis & Sanson-Fisher, 1998). Seventh, doctors should give patients a broad time frame

for the prognosis, one that is realistic to get any of their personal affairs together (Girgis & Sanson-Fisher, 1998). Eighth, doctors should avoid conveying that “nothing more can be done.” In their article, Girgis and Sanson-Fisher (1998) states that something can be done—providing reassurance in the form of medial and non-medical support for as long as needed to make the patient feel comfortable. Ninth, doctors should arrange a time to review the situation. That is, arrange for a time, preferably within 24 hours after initial diagnosis, to review the situation with the patient and/ or their family members (Girgis & Sanson-Fisher, 1998) to ensure successful transmission of information and answer any follow up questions. Tenth, doctors should discuss treatment options. Doctors are recommended to engage in dialogue with their patients, but the final treatment decisions are up to each patient. Further, if the patient is needing assistance with communicating the news and treatment plans to others, such as to their children, doctors should offer help to navigate that conversation (Girgis & Sanson-Fisher, 1998). Eleventh, doctors should provide information about the availability of support services, including support groups, palliative care services, hospice, and bereavement counseling for families (Girgis & Sanson-Fisher, 1998). The twelfth and final essential recommendation for doctors when breaking bad news is to take good notes and document any information shared. That is, to ensure that consistent information is available to all of the health care providers involved. Doctors should place into the written record how the patient reacted to the news, who is permitted to know about the patient’s condition and circumstances, and which family members have been told of the news about their loved one (Girgis & Sanson-Fisher, 1998).

Guidelines for delivering bad news is also specific to the receiver of the news. One such guideline is PACE (Garwick et al., 1995), which was developed to provide advice for clinicians that need to break bad news to families who have children that are diagnosed with a chronic condition. Based on the emotional reactions from family members participating in the study, families stressed that the content (current information) and the delivery (being sensitive) of such message are important. Therefore, Garwick and colleagues (1995) suggest to use the PACE model: *planning* the setting; *assessing* the family's background knowledge and experience; *choosing* strategies that best fit the family's particular situation, and *evaluating* the family's understanding of the information. Table 1 presents a visual summary of these three approaches.

The guidelines presented in Table 1 represent ways for health care professionals to deliver bad news to their patient. Across these guidelines, setting up a comfortable environment, assessing the patient's perception, knowledge, and understanding of the situation, and having a plan of action following the diagnosis are key points for health care professionals to take into consideration when delivering bad news.

Table 1

Summary of three different approaches for delivering bad news to a patient

<u>SPIKES</u> (Baile et al., 2000)	<u>Key Points</u> ² (Girgis & Sanson-Fisher, 1998)	<u>PACE</u> (Garwick et al., 1995)
S etting up: arranging for privacy	Arrange for privacy; Arrange for non-interrupted time	P lanning the setting
P erception: assessing what the patient already knows	Assess patients understanding and emotions	A ssessing the family's background knowledge and experience
I nvitation: determine how the patient would like the news	Provide information in a simple manner	C hoosing strategies that best fit the family's particular situation
K nowledge: give knowledge to the patient; provide warning	Encourage patients to express feelings Respond with empathy	E valuating the family's understanding of the information.
E motions: observe and respond to patient's emotions	Provide a realistic time frame for prognosis; Avoid expressing "nothing can be done"	
S trategy & Summary provide summary of meeting and plan of action	Review situation later; Discuss treatment options; Discuss support services; Document information shared with patient	

Although the guidelines provide insight into an approach that a physician could use to deliver bad news, some patients seem to differ with what is recommended. One discrepancy is found in actually delivering the news in a step by step method, as suggested by Baile and colleagues (2000) with the SPIKES model. Fujimori et al.'s (2007) study found that patients did not want the news to be delivered in such a manner.

² Girgis & Sanson-Fisher's (1998) key points were grouped together for consistency and ease of reading. This paper describes each point separately as the authors of the original article intended.

It appears that SPIKES employs a structure where the physician does most of the talking, resulting in little input from the patient.

Another discrepancy centers on the use of haptics (touch). A small percentage of patients (6.7%) wanted the doctor to touch their hands or shoulders (Furjimori et al., 2007), yet it is reported in literature of the benefit of using touch as an expression of positive communication and engagement between a physician and a patient during the giving of bad news (Girgis & Sanson-Fisher, 1998; Ptacek & Eberhardt, 1996).

Although there are a variety of recommendations available, Brown et al. (2011) suggests to tailor the bad news diagnosis to the preferences of the patient instead as this may increase patient satisfaction. In fact, they argue that all health professionals should know this skill set because the bad news may not directly come from an oncologist. However, this suggestion comes with a challenge: how to provide hope and optimism to the patient without being unrealistic.

Role of Culture

We have seen how a review of research provides a snapshot of how delivering bad news to patients is difficult for both the giver and receiver, even with guidelines available. Adding to this complexity is the role of culture in patient care. According to the National Institutes of Health (NIH), culture is the “combination of a body of knowledge, a body of belief and a body of behavior” (2017, par. 1). Culture impacts health care. The components of “language, thoughts, communications, actions, customs, beliefs, values, and institutions” (NIH, 2017, par. 1) influence and impact how people receive and utilize health services. Through their analysis, Rollins and Hauck (2015)

determined that there are two areas of how culture impacts the delivery of bad news to patients: the preferred disclosure of information and the involvement of family members.

Mitchell's (1998) classic review of the cultural issues in the disclosure of bad news to patients suggest that Western medical practitioners assume that the right to be fully informed is the "primary value of medical care and practice" (p. 153). Many patients in English speaking countries wanted full disclosure of their illness (Walsh, Girgis, & Samson-Fisher, 1998). However, most studies focus on race and ethnicity as a proxy for studying culture. Over twenty years ago, Blackhall, Murphy, Frank, Michel and Azen (1995) reported in a survey of an elderly population, that European Americans and African Americans preferred to be fully informed of their cancer diagnosis. However, Korean Americans and Mexican Americans were less likely to believe that a patient should be told of the cancer diagnosis and terminal prognosis. Years later, through a mixed method approach of the elderly population in California, Blackhall, Frank, Murphy, and Michel (2001) found similar results to their previous study. European Americans and African Americans preferred the truth telling (or disclosure) because it was a form of patient empowerment. It allowed the patient to feel in control of their medical decision making, including treatment options. Conversely, Korean Americans and Mexican Americans felt that truth telling is cruel and harmful to the patients (Blackhall et al., 2011). In contrast, elderly Korean Americans living in the New York wanted the doctor to tell them if they had cancer (Berkman & Ko, 2009). In addition, Ko, Nelson-Becker, Shin, and Park's (2014) study conducted with older Korean adult population in Korea, found that the patients wanted to know about their medical condition so that they could plan out their remaining time. The participants in this study

did not want an abrupt delivery, but did appreciate a slow, direct, but sensitive giving of the bad news (Ko et al., 2014). Elderly English speaking Japanese Americans and Japanese speaking Japanese Americans also preferred disclosure of the cancer diagnosis (Matsumura et al., 2002). This finding is similar to Gotay et al.'s (2004) research, where Hawai'i residents of Japanese and European ancestry believed that doctors should disclose a cancer diagnosis to the patient. While most cultures appreciate being well informed as a patient, not all caregivers agree. For example, Hispanic American caregivers preferred to keep their patient's prognosis a secret and behave or act as if the patient is getting well. This is done to protect the patient from learning additional information about their illness that could negatively impact their outlook (Kreling, Selsky, Perret-Gentil, Huerta, & Mandelblatt, 2010). In addition, some providers will soften their language by avoiding the word "cancer" in the delivery and replace it with "tumor" (Dohan & Levintova, 2007).

The involvement of family members is another important consideration in the delivery of bad news. Family members may differ on the sharing of bad news. For example, in a study of 75 Russian Americans, Dohan, and Levintova (2007) found that patients were open to the disclosure of the news, but their family members were against it. Bousquet et al.'s (2015) review found that in the United States, the doctor speaks to the patient first and then provide information to the family—if consented by the patient. In other cultures, such as in Iran, doctors disclose the bad news to the family first as this is considered to be an empathic and sensitive approach (Tavakol, Murphy, & Torabi, 2008). In Chinese culture, the patient makes decisions in conjunction with family members, but will defer to family for final decisions (Tse, Chong, & Fok, 2003). This is

aligned with Mexican and Korean Americans who favor a family oriented approach (Blackhall et al., 1995). It is not surprising to find that in many non-Western countries, family members stay in the hospital with their loved ones as this shows support and love (Lapine et al., 2001).

Similarly, in Fujimori et al.'s (2007) study, 78% of the patients preferred to be with members of their family when told. Braun et al (2002) had a similar finding. These results are in contrast to Scholfield et al.'s (2001) study where 44% of patients did not want anyone to be in the room when told, but if the patients had to have a person in the room, they prefer to have their spouse. This is similar to Butow et al.'s (1996) finding where patients preferred their spouse to be with them in the same room during the bad news transaction. The difference between these studies could be explained by cultural values. For example, Fujimori et al.'s (2007) study was conducted in Japan; Braun et al.'s (2002) study was conducted in Hawai'i, both displaying collectivistic orientation which focuses on family and relationship with others.

Doctors have noted the difficulty in delivering bad news to their patients (Bousquest et al., 2015). These two issues—disclosure of information and family members—could present an ethical and conflict of interest for physicians. For example, when physicians view information sharing as the patients right to know, but the family prefers to hide any medical information to protect their family member, it could be difficult to navigate this communication channel (Bousquet et al., 2015).

Summary

In summary, the giving of bad news to chronic disease patients occurs frequently. Patients and providers have various experiences and preferences for dealing with an

emotionally charged context. Patients tend to describe their experience of a bad news diagnosis as a process of before, during, and after. Patients also liked to be well informed and preferred to have their caregiver offer emotional support during the delivery of bad news. Physicians may experience elevated stress levels when delivering bad news, including physical sensations, despite years of clinical experience. The stress experienced by the physician may last beyond delivering the bad news itself. Although the role of nurses in the giving of bad news is not adequately described in the literature, nurses tend to provide information and support to the patient and family members. Interestingly, one of the reasons why professional caregivers find delivering bad news difficult is because they feel that they are not properly trained. Although published guidelines are available, most are based on opinion as there is little empirical evidence.

The role of culture complicates an already difficult situation, particularly with regards to disclosure preference and family involvement. The need for patient-centered and culturally responsive care is relevant in today's society, especially in an ethnically and racially diverse state like Hawai'i. For example, the State of Hawai'i Department of Health (2012) reports that the top three ethnicities that are present in the state of Hawai'i are Hawaiian (23.2%), Japanese (23.1%), and Caucasian (19.3%). Although this finding provides a helpful picture of the demographics, it should be noted that Hawai'i is not limited to a single ethnicity. The United States Census Bureau (2017) reports that in 2010, many people in Hawai'i identify themselves as being two or more races (23.6%). Although ethnicity is one indication of diversity, Hawai'i is a place that recognizes and honors multiple cultural norms and practices. Therefore, it is imperative to consider how diversity, including the limitation of race and ethnicity as singular categories, could

impact the communication styles and preferences of patients and provider.

The literature review supports the framing of the three research questions posed. Given Hawai`i's unique context and culture, it is important to consider what individuals in Hawai`i experience when informed of a chronic disease diagnosis and what we can learn from these patient stories to inform culturally responsive communication approaches. We also need to consider the nature of the educational experiences and training programs of health care professionals and nursing students relative to informing patients of a bad news diagnosis. This can provide a landscape of past and current practices of this communication experience. With these guiding questions supported through literature, we will look at the methodology of the study in the next chapter.

Chapter Three

Methodology

Three research questions guided the methodology used to conduct this study. A qualitative design was employed as a means to collect rich data about individual stories of a chronic disease diagnosis in Hawai'i in an effort understand their experience and inform culturally responsive care, and to learn about the experience and educational training of health care professionals and nursing students.

I begin this chapter with the concept of patient-centeredness and its relationship to the rationale for this study. Then, I explain the study design. I also describe the participants, instruments and procedures used to conduct the study. To conclude, I explain the study's trustworthiness.

Conceptual Framework

The choice of a patient-centeredness concept to inform this study was based on giving voice to those who are often left powerless when communicating about health care. Health professionals hold the power of advanced education, access to modern technology, and high social status, including scheduling and holding appointments on their jurisdiction and "turf" (du Pré, 2017). Thus, doctors have knowledge, abilities, social approval, and control over environmental proxemics that the public does not usually have. Given this, it is not surprising to find a power imbalance occurring, where the public (i.e. patients) may hold physicians in high regard. This may take place especially during medical interviews. With this inequity, patients may feel that they cannot contribute to such discussions with their provider. Further, health professionals may keep medical interviews concise to limit patient rambling (du Pré, 2017). As a result,

patients may feel powerless to speak up about their health concerns. This may limit the feeling of complete communication; thus increasing patient dissatisfaction and discomfort.

To recognize the power of individual voices, the guiding concept informing this study was patient-centeredness. Results from the literature indicate that there is not a clear definition of patient-centeredness (Epstein et al., 2005; Holmström & Röing, 2010). However, it is noted that “patient-centered communication focuses on the patient as a ‘whole person’ in the context of his/her psychological and social circumstances” (Sparks, Villagran, Parker-Raley, & Cunningham, 2007, p. 181). Epstein et al.’s (2005) research suggests that an operational definition that includes eliciting and understanding the patient’s perspective, understanding the patient within his or her unique context, and reaching a shared understanding of the problem and its treatment that is aligned with the patient’s values.

Epstein and colleagues (2005) state that patient-centeredness has its roots in three core values: 1) considering patients’ needs, wants, perspectives, and individual experiences, 2) offering patients the opportunity to provide input and actively participate in their care, and 3) to enhance a partnership between physicians and patients. Key points of what patient-centeredness represents is highlighted in Mead and Bower’s (2002) review of the literature. These points include that the caregiver gives attention to biological, psychological, and social aspects of patients’ health; the caregiver understands the patient as a person and that illness has a personal meaning for each individual; the sharing of power and responsibility where the provider is sensitive to the patient; each party makes mutually satisfying decisions to reach a common goal; awareness of health

care provider as a person and that their personal characteristics may influence medical communication (Mead & Bower, 2002; Mead & Bower, 2000). It is argued that patients are experts of their own bodies (Holmström & Röing, 2010). This distinction is individualized, which suggests that each health experience is personal.

From a social constructivist perspective, understanding the world stems from shared interactions of people and their environments (Collins, 1994). In a health context, physicians and patients provide viewpoints (that could be opposing) to the medical encounter (Ishikawa, Hashimoto, & Kiuchi, 2013). Thus, disease and illness is shaped and best understood through these social interactions (Lupton, 1994). Yet, how to tell cancer patients bad news relies mostly on the opinion and experiences of the physician (Salandar, 2002). Therefore, it can be suggested that collaborative communication between the physician and patient does not often take place in this type of interaction.

It should be noted that the studies conducted in the giving of bad news have focused on race and ethnicity as a way of studying culture and their communication preferences. This is problematic in two ways. First, Hawai`i provides a cultural landscape of multiple ethnicities and cultural backgrounds. With such diversity, it is likely that patients and doctors will communicate with people who are different from each other. Second, limiting to just ethnicities as a unit of measure is a cause for concern. Epner and Baile's (2012) research stresses the importance of cross cultural approaches to culturally competent clinical practice. With such variety of cultural customs and norms, there is a natural tendency for the desire to create a "cheat sheet" or some system of how people of different ethnicities communicate, but doing this over simplifies a complex phenomenon that can lead to stereotyping (Kleinman & Benson, 2006; Rollins & Hauck, 2015). Given

this, recognizing the voices of those that have been diagnosed, as I have done with this study, provides more knowledge on patient-centered approaches to communicating competently.

In addition, recognizing the voices of various health professionals and nursing students, whose voices are also a part of this study, are also valuable and contribute greatly to the understanding of being the other side of patient-centered care. They provide the lived experiences of their educational training and hands on perspectives that cannot be obtained through textbooks or any other means.

Current research does not address the diversity of these voices who live in Hawai'i in relation to chronic disease diagnosis. Nor does current research examine the gaps from what is experienced from a patient and what is learned through provider education and training. Therefore, an opportunity exists to learn from the stories of participants in this study combined with health conditions that are not often connected to bad news diagnosis.

Study Design

This study used a basic qualitative research design. The purpose of this research is to “understand how people make sense of their lives and their experiences” (Merriam, 2009, p. 23). A feature of conducting qualitative research is to empower others through the telling of personal stories (Creswell, 2013). With this approach, “the researcher is interested in understanding the meaning a phenomenon has for those involved” (Merriam, 2009, p. 22). Merriam (2009) further explains that researchers who engage in this type of research are those who are attracted to “how people interpret their experience, how they construct their worlds, and what meaning they attribute to their experiences” (p. 23).

According to Patton (2002), qualitative content research is “any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings” (p. 453). Through rigorous subjective interpretation of examining, coding, and creating themes, qualitative content analysis provides descriptions from participants “reflecting on how they view the social world” (Zhang & Wildemuth, 2009, p. 309). This type of analysis “allows researchers to understand social reality in a subjective but scientific manner” (Zhang & Wildemuth, 2009, p. 308). This approach is valuable for studying the individual voices of patients and the impact of their own social contexts on their experience of care, as well as how those same dynamics affect health care providers.

The current study explores two areas using three populations. First, to capture experiences, emphasis was placed on the stories of those who were diagnosed with chronic disease as this effort highlights the concept of patient-centeredness. Second, to gain insight into the training and of the experiences of nursing students and health care professionals, written narratives in the form of a brief questionnaire were used. This triangulation is appropriate as it seeks to understand the experiences and values of an individual from three different participant perspectives (Creswell, 2013). Creswell (2013) further adds that when a theme emerges from a variety of sources, the insight provides validity to the study.

Participants

As stated, the participant population of this study is comprised of three different adult groups. The first group are those who identify themselves as having been diagnosed at some point in their life with a chronic disease. Inclusion criteria for these participants

comprised of those being over 18 years of age and diagnosed in Hawai`i with a chronic disease by a physician at least once in adulthood. Four interviews were conducted on the Big Island of Hawai`i and two on the island of O`ahu. These particular locations in Hawai`i were selected due to the proximity to the researcher and because of participant relationships with future participants as referral sampling was used. Of the six participants, five were female and one was male. Chronic conditions included various forms of cancer (two breast and one thyroid), allergies, diabetes, and psoriasis.

The second group consisted of those who identify themselves as health care professionals. Inclusion criteria for participants comprised of being a current licensed professional health care professional, be educated in Hawai`i within their chosen profession, and be of at least 18 years old. Health professionals consisted of a variety of professions, including nursing. This wide inclusion was to capture the firsthand accounts of their experiences and perspectives of individuals providing care. Their insights provide valuable information into understanding health care professional's needs in terms of future training.

The third group consisted of those who identify themselves as nursing students. Inclusion criteria for these participants comprised of being a student that is in a nursing degree seeking program, be attending a university or community college in Hawai`i, and be of at least 18 years old. Ten written narratives were from students currently enrolled in the Bachelor of Science in Nursing at the University of Hawai`i at Hilo (UHH).

As previously noted in the literature, nurses are the support and educational liaison for patients. In some cases, they become the person to deliver the bad news when the patient did not understand what the doctor said (Dewar, 2000). Nursing students are

in training and will encounter, if not already, situations where they will have to give unfavorable news to their own patients. Therefore, there is good reason to understand their experiences and current education of this topic.

Instruments

For this study, two instruments were used: one-on-one interviews and qualitative surveys. The purpose of interviews is to obtain information from another person (Merriam, 2009) and is often used to “enter into the other person’s perspective” (Patton, 2002, p. 341). As Merriam (2009) points out, interviewing is a necessary research instrument to use “when we cannot observe behavior, feelings, or how people interpret the world around them” (p. 88) and used when “we are interested in past events that are impossible to replicate” (p. 88). Therefore, the experiences shared are the recollection of memories. Similar to interviews, qualitative questionnaires comprise of memories, opinions, and experiences of a specific situation (Rivano & Hagström, 2017). Given this, open-ended questionnaires function much like an interview.

Data Collection/Procedure

Full board approval from the Institutional Review Board (IRB) was established in August 2016 (Appendix A)³. Data collection began soon after and continued until December 2016. The IRB approved the consent forms (Appendix B), recruitment scripts (Appendix C), and interview questions and qualitative questionnaires (Appendix D).

Semi-structured interviews were conducted with each participant who received a chronic disease diagnosis. Questions such as *what values and practices are important to*

³ As reflected in appendences, the original title of this dissertation was *Developing Communication Competencies in the Giving of Bad News*. The current title of this study developed organically after interrupting the findings.

you in your life? and *how did the doctor inform you about your diagnosis?* were used. Recruitment for these participants occurred initially through social media (via Facebook) with an approved recruitment script. My electronic post was then shared by three family members, two of whom have had chronic disease diagnosis themselves. I attempted this type of recruitment because of my family's health experiences and community relationships that resulted in various connections with people living in Hawai`i. Since this approach yielded one participant, I decided to use referral, or snowball, sampling from that one participant. Merriam (2009) describes this strategy as “locating a few key participants who easily meet the criteria you have established for participation in the study” (p. 79) and considers this method as one of the most common form of purposeful sampling. That connection lead to other interviews. Each participant was invited to do the interview via email. Once at a location of the participant’s choosing, I provided a consent form for their review and signature. Interviews were between 45-120 minutes each and recorded with multiple devices. For their participation, each respondent received a \$5 gift card to Starbucks or Jamba Juice. This gratis was given at the conclusion of the interview.

Due to the uniqueness of this study, a qualitative questionnaire used for the specific scope and depth of this topic that was lacking in the literature; therefore, a four item qualitative questionnaire was developed. These open-ended questions were used for both health care professionals and nursing students with respect to learning about their experience and training in delivering bad news to patients. Questions such as, *what has been your experience in communicating bad news?* and *how might educators support training in this area?* were used.

Like the interviews, I initially attempted recruitment via social media because of my family's health experiences and community relationships that resulted in various connections with people living in Hawai'i. This approach did not yield a health professional participant. The same recruitment style was used for nursing students. This approach yielded five participants.

To gain more participants, I inquired with a committee member who is also the Director of Nursing at UHH. The director offered to distribute surveys to her network of health professionals and to her third year nursing students who were enrolled in an upper division class for Fall 2016 semester. The surveys were collected by the director and I was able to pick them up from the nursing program's secretary. This resulted in ten surveys for health professionals and ten additional surveys (15 total) for nursing students. All participants were not current colleagues or students of mine. After the submission of the survey, each respondent received a \$5 gift card to Starbucks or Jamba Juice as a gratis. All participating students were able to retrieve their gift cards from the nursing program's secretary during the regular work hours of that week.

Due to the sensitive nature of the study and at the request of IRB, I collected, arranged, and prepared a handout containing contact information for free counseling services at the UHH and at the University of Hawai'i at Mānoa. Private counseling was also an option provided. This service was readily available for any participant by request, as mentioned in the consent form. Once the audio recordings were transcribed, content analysis followed. All materials were located in my office cabinet during the transcribing and data analysis process. All audio and written materials were destroyed following data analysis.

Data Analysis

Content analysis was used to assess participant recollections about receiving a bad news diagnosis and health professionals' and nursing students' experiences of training on this topic. This approach “involves a process designed to condense raw data into categories or themes based on valid inference and interpretation” (Zhang & Wildemuth, 2016, p. 308) and is commonly used in nursing research (Elo & Kyngäs, 2008). Coding “involves aggregating the text or visual data into small categories of information...then assigning a label to that code” (Creswell, 2013, p. 184). A deductive approach was used.

Deductive approach is based on previous knowledge where the researcher reexamines existing data given its new context (Elo & Kyngäs, 2008). Since categories are already formed from previous knowledge, data from the interviews were coded accordingly. Since patients experience their diagnosis in terms of a process (Salandar, 2002; Tobin & Begley, 2008), the data analysis adhered to the organizational pattern of before, during, and after the bad news.

Before. One participant mentioned, *I mean, I kind of already knew. I had that sense that something was wrong...because you know your body* (Leilani Fields) was coded as *before* the diagnosis. This is because the participant had a gut feeling about her condition prior to the official diagnosis.

During. What occurs during the delivery of bad news provides an important insight into what transpires. Following the organizational structure of Ptacek and Eberhardt (1996) and Ptacek and Ptacek (2001) work, the responses of what occurred during the delivery of the news were grouped into four clusters, including what was said

during the delivery, how the news was delivered, what behaviors the physician displayed, and the environment in which the news was delivered.

A deductive approach was also used to analyze the data provided by health professionals and nursing students. Based upon the four item qualitative questionnaire, categories were formulated, including protocol used, experience(s), role of culture, and training recommendations. For example, the following quote explained one health professional's *experience* in the emergency room.

You never knew how someone will react. Some people just say ok and walk out, some people scream and cry. I've had a spouse hug me and then started to pound me in the chest. So I let her until she was done. Be prepared for anything.

[Registered nurse (RN); Emergency Room (ER)]

After. Part of understanding a person's experience of a chronic disease diagnosis is learning about what occurs after the delivery. This statement, *they would actually call the house to make sure everything was okay and whatnot* (Kaleo Young), was coded as *after* the diagnosis since the check-in phone calls occurred following the diagnosis.

The examples presented here represent the thoughtful coding process that took place for the interviews. The same effort was made to the qualitative surveys from the health care professionals and nursing students. Throughout the coding process, the written materials were read repeatedly and at different points of time as a way to recognize if any information was missed with each passing. This was to ensure the proper collection and categorization of the participant's thoughts.

Trustworthiness

Careful attention to the way which data are collected, analyzed, interpreted, and presented are important considerations for trustworthiness and rigor, or validity and reliability (Merriam, 2009). Ensuring credibility is one of the most important factors in establishing trustworthiness (Lincoln & Guba, 1985) and requires conducting the research in an ethical manner (Merriam, 2009). Merriam (2009) further adds that that there are strategies that can be used to increase the “credibility” of a qualitative researcher’s findings. Internal validity, external validity, reliability, and objectivity that is rooted in quantitative research is often noted in qualitative research as credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Credibility. Merriam (2009) explains that credibility, or internal validity, is concerned with “the question of how research findings match reality” (p. 213). Although Maxwell (2005) states that no one can really capture reality, Merriam (2009) points out that qualitative research investigates people’s constructions of reality and how they understand or interpret the world.

The two ways that the present study strived to attain credibility was to use triangulation and member checks. Triangulation is the process of “corroborating evidence from different sources to shed light on a theme or perspective” (Creswell, 2013, p. 251). Triangulation is possible by using multiple sources of data, such as interview data gathered from a variety of people who share different perspectives, as a vehicle for comparing data (Merriam, 2009). This study used three points of perspectives: those who were diagnosed with a chronic disease, and the education and experiences from health care professionals and nursing students.

Member checks is the process of having the participants read and review the transcripts of the interview(s) to solicit feedback, with the emphasis on whether what is said is matched (Shenton, 2004). This process is considered the “most important way of ruling out the possibility of misinterpreting the meaning of what participants say and do” (Maxwell, 2005, p. 111).

This study conducted member checks with the participants who completed the interview. After the analysis was completed, participants who received a chronic disease diagnosis were provided excerpts via email from their interview, for their review. Excerpts were provided since much of the introductory and concluding dialogue were focused on relationship building and reconnecting between myself and the participant. Thus, these statements were not factors in describing their experience of receiving bad news about their illness.

During the member check process, I asked each participant if they would like to create a pseudonym. Half of the participants provided a first and last name to use for this research. The other half gave me permission to create a name for them. The health care professionals and nursing students were randomly assigned a number.

Transferability. Merriam (2009) explains that transferability, or external validity, is “concerned with the extent to which the findings of one study can be applied to other situations” (p. 223); thus, demonstrating and applying the results of the work to a wide population (Shenton, 2004). However, qualitative studies are relatively small so it is difficult to apply findings broadly (Shenton, 2004). If the researcher is able to provide enough contextual information, it is possible that a reader may relate the findings to their own situation (Lincoln & Guba, 1985). In the present study, the researcher was careful to

provide rich descriptions of the findings in a way that could be applied to, explain, or transfer to a reader's situation.

Dependability. Dependability, or reliability, refers to “the extent to which research findings that can be replicated” (Merriam, 2009, p. 220). Therefore, if the research is repeated (same context, methods, participants), could similar results be established? (Shenton, 2004). However since human behavior evolves, Merriam (2009) argues that personal experiences are not unreliable or any less valuable and if the “findings of a study are consistent with the data presented, the study can be considered dependable” (p. 222). Shenton (2004) suggests that the study should be reported in detail, enough for a future researcher to repeat the study should it be done so. In this study, extensive procedural information is provided; therefore conducting a replicated project with the similar structures is possible.

Confirmability. Confirmability, or objectivity, is the process to ensure the research findings represent the participants' voices and not the researcher's bias and preferences (Shenton, 2004). In addition to triangulation, an audit trail is a useful tool for addressing confirmability. Merriam (2009) describes an audit trail as a descriptive account of “how the data were collected, how categories were derived, and how descriptions were made” (p. 223) in an effort to remain objective while engrossed in the data. In this process, a journal is helpful for reflecting and grouping information on the participants' accounts of their experiences.

Summary

As a basic qualitative design, interviews and open-ended questionnaires served as instruments for this study. Participants included three groups: those who were diagnosed

with a chronic disease, health professionals, and nursing students. Content analysis followed, with respect to trustworthiness and credibility. Findings are presented in the next chapter.

Chapter Four

Findings

This chapter presents the data analysis of responses from three groups of participants: individuals who were diagnosed with a chronic disease, health care professionals, and nursing students. To learn about what individuals in Hawai`i experience when informed of a chronic disease diagnosis and to understand their stories to inform culturally responsive care, interviews were conducted with those who were diagnosed. To acquire information on what health care professionals and nursing students experience and learn when informing patients of a chronic disease diagnosis, a qualitative questionnaire was distributed.

Interviews

Six adults participated in a face-to-face interview, lasting up to 120 minutes per person. Of the six interviews, five were female and one was male. All participants were diagnosed with a chronic disease in Hawai`i at some point in their adult life, but their chronic conditions varied from cancer (breast, thyroid), allergies, diabetes, and psoriasis. All but one participant grew up in Hawai`i (three on the island of O`ahu, three on the island of Hawai`i, and one in Missouri), and all participants are currently living in the state of Hawai`i. Narrative statements were used to document their recollections and to affirm their verbal statements about receiving bad news of their chronic disease. Using a patient-centeredness approach in working with participants honors their story, greatly contributing to understanding their experience.

Patient Experiences. The first research question asked, what do individuals in Hawai`i experience when informed of a chronic disease diagnosis by a physician? I

structured the analysis around three concepts, including how patients reflected on their experience in terms of before, during, and after the bad news diagnosis (Salandar, 2002; Tobin & Begley, 2008).

Before. Five of the six participants acknowledged they were the ones to notice that something was not right with their body, which led to an appointment with a doctor, *I mean, I kind of already knew. I had that sense that something was wrong...because you know your body* (Leilani Fields). After feeling a lump in the breast in the same spot for the second time, another participant felt compelled to ask the doctor for an earlier appointment.

I called my gynecologist and I said, 'Hey, you know we're supposed to have our appointment a month from now, but I felt this lump so could I just come in early'? (Irene Latkjohn)

One participant commented that self-monitoring was ingrained from a young age. Self-exams became routine due to a family history of breast cancer.

I think from early on as a young woman, it was kind of impressed on us that you do a monthly self-exams and look for abnormalities and then I don't really think I did it regularly, but I think once my mom and my sister, especially, went through their cancer that I became more vigilant to make sure that I was doing it regularly...they would give you little pamphlets of how to do a breast exam and then show you how to make sure you're touching all the areas either lying or standing and what positions to make sure that you're being able to feel any lumps. I think they always stress it's a good preventative way of catching something early. (Leilani Fields)

These three examples show how the participants took the initiative when they felt that something was not right with their body. They acknowledged an uncertainty about their well-being and acted to find more information. This finding supports Blackhall et al.'s (2011) research that suggest patients intuitively know that they are sick.

During. Ptacek and Ptacek's (2001) study on the perceptions that patients have on receiving bad news served as the base for how I chose to examine what individuals experience when informed of a chronic disease by a physician. In keeping to previous literature (Ptacek & Edhehart, 1996), Ptacek and Ptacek's (2001) study used descriptive statements of cancer-specific news in four key areas, including what was said in the delivery of the bad news (e.g. warning shot); how the bad news was delivered (e.g. warmth); what behaviors the physician displayed (e.g. eye contact, touch); and the environment in which the bad news was delivered (e.g. phone call, face to face). Given the broader context of chronic diseases, the structure from the Ptacek and Ptacek (2001) study asserted that this was an appropriate starting point to document individual experiences as a means to learn what is communicated verbally and nonverbally by the physician disclosing the bad news and its impact on the patient. This became the framework I used in interviewing participants in this study.

What was said during the delivery of the bad news? The first area examined what was said by the physician to the patient in the diagnosis. What is said during an interaction plays a significant role in the process of communicating. A component of communication is meaning creation (Alberts, Nakayama, & Martin, 2016). Each message that we send (or encode) includes two types of messages—content meaning and relationship meaning. Content meaning includes anything that is communicable

regardless if the information is true (Watzlawick, Beavin, & Jackson, 1967). Relationship meaning is how the messages should be taken as; for example, *this is how I see you*. (Watzlawick et al., 1967). Given this distinction, what is said during an interaction is a reflection of content meaning of message creation.

Results showed varied responses as there were significantly different experiences among the participants. One narrative indicated that while the doctor was performing an ultrasound to determine if cancer was present in the breast, the doctor already gave a warning shot of the bad news. The doctor told the participant, *"I'm just going to be honest with you. This doesn't look particularly good, but I want you to get a second opinion"* (Irene Latkjohn). The second opinion doctor also provided a warning and said, *"It's a very rare case that this isn't cancer"* (Irene Latkjohn). Ultimately, it was a nurse—not the doctor—who communicated the news and asked the participant to come in to the office later that afternoon. Similar to the physicians, the nurse also provided a warning shot—one that is constructed as apologetic—when revealing the news.

"I'm sorry to tell you this news over the phone, but you have invasive ductal carcinoma. We wanted to let you know as soon as we could". I was like, "Oh my gosh. What does all this mean"? She said, "Well there's a lot more information you're going to need. Can you come in and meet with our oncology surgeon at 2:30 today"? I said, "Yeah. I'm supposed to be meeting my friend at Tiki's but yeah I guess I can fit it into my schedule". I said, "Yeah". And she said, "That's all the information I have for you. I'm just the nurse". (Irene Latkjohn)

According to Baile et al. (2000) and Ptacek and Edherhert (1996), it is recommended to give a warning to the patient prior to the actual delivery of the news. This helps to buffer

the news and allows the patient to be mentally prepared.

After receiving a diagnosis of thyroid cancer for the fourth time, another participant specified that the doctor not only provided a choice when revealing the news, but lead a prayer.

My endocrinologist, she told me, "It came back and what are we going to do"? I was in tears. I said, "Okay well, again, I have to remove myself and rationalize. You know what works. Surgery works". She gave me an option of radioactive surgery. I told her, "Yeah, but that's only 50/50. Let's do what works. Let's do the surgery, take it out, do the radioactive therapy to kill whatever's left. Then we go from there". I'm a Christian. I only had that one thought in my mind, the Lord would not give me more than I can handle. It was surprising because that phone call that I had with the doctor, related to me that she was Christian as well. She knew my religious practices. She said, "You know what, let's pray". Here we are, outside of Lyman museum, I'm sitting on the curb, if you can imagine, Haili Street. I'm on the phone and we're praying. She's praying for me, and I felt comforted. (Kit Brown)

The aforementioned experience highlights two things. The first is that the physician provided an option to the patient. This allowed the participant to have choice with their care. The second is that the physician was emotionally consonant by recognizing the faith based practices of the patient. This type of communication allowed the participant to feel valuable and at ease with the provider.

Other participants indicated that their diagnosis conversation focused more on the physician giving instructions or issuing directives. An example of this occurred when the

doctor said, *“Here is what you have to do for the rest of your life” ...he told me to do it, I did it. I didn’t ask any questions* (Kaleo Young). Another participant echoed similar statements, as the doctor explained, *“Oh, take these pills”* (William Kapena). The latter participant went on to explain the dissatisfaction felt with the provider’s communication style. These examples highlight a traditional form of caregiver-centered communication. In place of building partnerships and supportive communication, health professionals use their talking time to ask questions or issue directives, such as instructions or commands (du Pré, 2017). This is not necessarily viewed as a negative response, as this could be the physician’s way of being engaged and act as an advocate on behalf of their patient’s health. This style of communication may provide the patient with a clear direction when faced with uncertainty.

Although directives were used by some physicians, other physicians in this study exhibited language use that reflected collaborative communication and additional information sharing. Although language use (avoid jargon, uses simple words, etc.) is noted in research (Girgis & Sanson-Fisher, 1998; Ptacek & Edherhert, 1996; Ptacek & Ptacek, 2001) as important, I felt it was logical to place this component in the “what is said” category since it reflects content.

Some participants discussed how the physicians provided them with a choice for their direction of care.

He also recommended, he said, “You know think about it. Decide what you want to do. Maybe also go for a second opinion. I’m eager if you wouldn’t mind sharing with me their deliberation process”. (Irene Latkjohn)

This type of communication helped to establish the feeling of working together, as

another participant noted.

She goes, "Do you want to try this or do you want to try that? If it doesn't work, we can try something else". What else can you do? That's all you want. We'll try it. I don't care if it doesn't work. I'm not looking for the perfect solution every single time because it's a work in progress. I'm going to work together with you to figure out the solution. As opposed to you just tell me what to do. Which was the first doctor. I'm going, "It's not working". If you're not going to listen to me. Then I'm not coming to you. (William Kapena)

One participant mentioned that having a choice allowed time to reflect and think about what the future care plan would be.

She allowed me the choice. Okay so what do you want to do? It wasn't the okay, this is the procedure that we decided. This is what we're going to do. She allowed me to decide for myself what steps I wanted to take in this. Being approached that way first, before the prayer, really helped me to say, okay, it came back. I'm not a stranger to this. This is what we're going to do. (Kit Brown)

This finding supports the collaborative medical communication framework. This process establishes patients and caregivers as peers who openly discuss health options and make mutually satisfying decisions (du Pré, 2017). Patients work with their caregivers as partners in a cooperative manner.

Another aspect of language use that emerged is one in which information is provided to the patient. One participant explained that being informed of the next steps helped to have a clear understanding for future care.

She said, "All right we're going to get through this. This is what we're going to

do". Seeing that procedural side of everything that helped me remove myself emotionally from myself. (Kit Brown)

Another participant reflected on how the physician provided information outside of the usual prescribed medication.

He's the one who said, "You should exercise every day for at least 30 minutes" even before anybody else was saying anything. Then the thing with taking the B12 and the vitamin C, and really providing you with that knowledge. (Kaleo Young)

Tobin and Begley's (2008) research indicates that following a bad news diagnosis, patients move from knowing to needing to know. In other words, the diagnosis was a disturbance of their everyday living that challenged their sense of normalcy; therefore, there's a sense of urgency of needing information. Providing resources—that is, additional information—made a difference in creating a future care plan.

I did feel better because the other thing was that they gave me resources. That's how I found out about Mayo Clinic and Johns Hopkins, because those were the referrals that they give. It's either to them or to the UCLA [University of California, Los Angeles] Medical Clinic. (Kaleo Young)

This statement compliments Tattersall et al.'s (1994) research on informational aids, where it was shown that having information in between the diagnosis and next visit was helpful and beneficial to the patient and their families.

Having clear communication and information is seen as especially important. One participant questioned how much of the information is really understood by a patient.

I think we want to be able to rely on the medical expertise that's there, but then how much of it do we, as laypeople, do we understand... Especially when you're

going through it yourself with some shutdown of what normally maybe perhaps you would be able to comprehend, so really having to ensure you are understanding. (Leilani Fields)

One participant commented that having information—or lack of—affects trust.

For me, more information is better than no information. Even bad information is better. Give me everything. Don't sugar coat it. Just give me the truth and be honest. Be truthful. You're not saving me from anything by sugar coating it. Don't lie to me. Don't think you're doing me a favor by lying to me. Once I find out you lied to me, I'm never going to trust you again. (Anita Jones)

These insights are similar to what is presented in existing literature. Patients prefer content—whether it is good or bad news (Brown et al., 2011) and did not like it when the physician was vague (Fujimori et al., 2007).

In summary, the first area examined was *what* was said by the physician to the patient in the diagnosis. Findings showed varied responses. Warning shots and leading a prayer were used. While these highlight positive communication practices for delivering bad news, the third finding suggested that physicians still utilize traditional caregiver-centered communication. While authoritative direction by the caregiver is not always seen as a negative experience, it was not interpreted as a beneficial experience by the participants in this study.

In contrast to the caregiver-centered communication, other physicians in this study also used collaborative communication. Several participants mentioned how their physicians provided them with a choice for future care. This helped to give the feeling of partnership. In addition, participants were informed of the next steps of their care,

including supplemental information such as brochures.

How the bad news was delivered. The second area examined how the bad news was communicated, such as emotional appeals, warmth, caring, empathy, and respect (Ptacek & Edherhert, 1996; Ptacek & Ptacek, 2001). Returning to message creation, a component of communication, relationship meaning is what the message transmits or suggests about the relationship (Watzlawick et al., 1967). This suggests that how the bad news was delivered by the physician is connected to relational and supportive communication.

In regards to displayed emotional communication by the provider, one theme emerged: empathy. Several physicians in this study communicated empathy by relating the illness to their own personal lives and freely disclosing this with their patients, *she's one of the best doctors I've ever had...Her empathy towards me was [shown] because her family members had the same illness* (William Kapena). Another comment was similar, *I think he was very sympathetic towards his patients because of his daughter* (Kaleo Young). In one instance, the participant commented that the physician thought about how to treat the illness in relation to his wife, *He said, "If my wife were in your shoes," because he has a wife and young children...He said, "If she were in your shoes, I would want her to do everything she possibly could"* (Irene Latkjohn).

One of the reasons why delivering bad news is difficult for physicians is that doctors may have a personal fear of illness and may keep at a distance to protect themselves. The conversation may “hit close to home,” reminding physicians of their own mortality or of the possibility of a similar fate for a family member (Ptacek & McIntosh, 2009). In the described experiences, the physicians did the opposite—by

relating the illness to their own family. This communication style exhibits empathy.

This communication style could also be the result of social penetration theory (Altman & Taylor, 1973, 1987). Social penetration theory suggests that relationships develop through self-disclosure. By sharing information about ourselves to others, reciprocal relationships form. The experiences suggest that the participants and their physicians felt somewhat comfortable with each other—enough to where the physician disclosed something personal about himself or herself.

Communicating empathy is an important consideration for patients. As one participant explained, *it was that empathy that he showed that made me trust him* (Kit Brown). Expressing empathy is a recommended guideline for delivering bad news (Baile et al., 2000; Girgis & Sanson-Fisher, 1998).

In summary, the second area looked at how the bad news was delivered. This includes emotional appeals and language use (Ptacek & Edherhert, 1996; Ptacek & Ptacek, 2001). Empathy was a strong component in the participants' reflections. In regards to emotional communication displayed by the provider, several physicians in this study communicated empathy by relating the illness to their own personal lives and freely disclosed this to their patients. Compared to the literature, this is an unusual finding.

What behaviors the physician displayed. The third area examined the specific communication behaviors that the physician displayed while giving the bad news. Kinesics (eye contact), haptics (touch), and chronemics (time) emerged as the behaviors that physicians displayed. These three areas reflect the value of nonverbal communication in these types of interactions. As one participant explained, the lack of eye contact—a form of kinesics—during the interaction was not an issue of concern. In fact, it was

described as something positive, *when he closes his eyes when he talks to me, I interpret that as him being really thoughtful or trying to come up with the right words to make sure that he's sharing the information clearly* (Irene Latkjohn). This finding is in contrast to the recommended guidelines provided in previous literature (Baile et al., 2000), where it is suggested to establish and maintain non-threatening eye contact with the patient.

While describing the experience of being diagnosed for the third time, the participant reflected on haptics—or being touched by the physician.

He came up to me and he said, "You know, I came back so we're going to be keeping an eye on you". It was a gesture that he made. He touched my shoulder.

He was like, "We're going to be watching you now". (Kit Brown)

A touch on the shoulder during the delivery of news was seen as a positive experience, according to this participant. This thought is aligned with research as it is suggested by recommended guidelines to use appropriate touch when disclosing the bad news (Girgis & Sanson-Fisher, 1998; Ptacek & Eberhardt, 1996). This helps to convey warmth and positive engagement. However, Fujimori et al.'s (2007) research indicated that a small percentage of patients wanted the doctor to touch their hands or shoulders.

Chronemics—or the study of using time—provided the foundation for the next finding. Providing time for the patient to digest the information was helpful. One participant commented, *she gave me my personal space to where I was able to take a minute [and] re-group myself by just what she told me* (Kit Brown). Another participant also expressed a similar thought, *he tried to spend 30 minutes with you* (Kaleo Young).

Part of setting the stage for delivering the bad news is to nonverbally demonstrate that the physician is not rushing through it. This is shown by sitting down with the patient

and allowing the patient to digest the information presented, as suggested by recommended guidelines (Baile et al., 2000).

In summary, the third area examined the specific communication behaviors that the physician displayed while giving the bad news. Three areas of nonverbal communication emerged: kinesics (eye contact), haptics (touch), and chronemics (time). Participants did not mind the lack of eye contact, but appreciated the use of supportive touch and having time to process and absorb the information. This finding relates to the fourth aspect of describing the experience of a bad news diagnosis: the location of where the news is delivered.

The environment in which the news was delivered. The fourth area of describing a participant's experience was the place in which this type of communication occurred. As such, participants recollected the communication channel that was used in the delivery of the news of their chronic disease. Of the six participants, two learned of their diagnosis over the phone and two participants learned of their diagnosis in the doctor's office in a face-to-face conversation. The remaining two participants had multiple diagnoses for the same disease and learned of their diagnosis in both communication channels—via phone and face-to-face conversation.

Upon learning about the diagnosis via phone call, participants were split in their liking for this mode of communication. One participant was satisfied of learning the diagnosis over the phone because it meant retrieving information quicker.

I was glad. I was actually relieved, because I didn't want to have to wait until the next week because I was going in thinking, "I've got to wait all the way until the next week. How am I going to wait"? The waiting is awful. It was actually good to

find out. If they would've said, "Come in, you can meet with the doctor at 2:30". And tell me at 9:30 in the morning, I would've spent all day going, "Just tell me. Just tell me". You know? I wouldn't have wanted to wait. (Irene Latkjohn)

However, one participant felt that a phone call was not the most appropriate way to share a diagnosis.

To hear on the phone was, I think, not a good way to share this kind of news...I picked up the phone and I got into the conversation. I guess I could have said, "Oh no, if they're calling me I know it's something. I could have waited," but I didn't, so I have to have ownership of that too. I don't know why they would think that that's okay. (Leilani Fields)

Of those that received the diagnosis in person, one participant mentioned how the location was not a conducive environment, *we were in the basement. I just thought it was almost like they were there to help you but they really didn't want to help you. Nothing was matter of fact (Anita Jones)*. Although this experience describes a face-to-face interaction, it points out that the specific location of the news—in this case, a basement—played a role in the negativity of the experience.

One participant, who was diagnosed four different times with the same illness due to recurrent thyroid cancer, had three diagnoses given in person at the doctor's office. The fourth diagnosis was delivered via phone call. The participant stated that receiving the news over the phone (in comparison to face-to-face) was the result of living on a different island than the doctor, *it had to be done because the doctor was in Honolulu [O'ahu]* (Kit Brown). This is a common reality for inter-island residents whose doctor may be on another island. Therefore, stating the news over the phone may be the only

way to give it. Yet, delivering the bad news in-person is aligned with best practices (Baile et al., 2000), which is supported in research as a patient preference (Fujimori et al., 2007; Schofield et al., 2001).

In summary, the communication channel that was used by the health care professional was the fourth area of describing participants' experience. This included a phone call, face-to-face conversation in a doctor's office, and both (phone call and face-to-face conversation). The latter occurred with participants who were diagnosed more than once for the same chronic disease.

The experience of learning the news yielded mix findings. While there was satisfaction in learning the news over the phone, this was due to the participant's desire to retrieve information as quickly as possible. Yet, another participant expressed distaste for learning the news in this way, but took ownership of answering the call in the first place. One participant, who had the four diagnoses—the last one received over the phone—was the result of living on a different island than the doctor, so there was not an option to learn the news any other way. Of those that received the diagnosis in person, one participant mentioned how the location was not a favorable environment to learn of the news.

After. Participants commented on life after the diagnosis. One theme that emerged was the continuing support that was given by the health care professionals. One participant explained the appreciation for the support provided, *I always thought of how just fortunate I was or I am. To not just have the support from family members, but also from the medical profession as well* (Kit Brown). Another participant pointed out that the physician reached out and made phone calls to check-in, *they would actually call the*

house to make sure everything was okay and whatnot (Kaleo Young). Another participant mentioned that the provider was able to offer ways to keep living.

When I wanted to do that half-marathon, she said, "Okay. We'll find a way for you to do it". She was just the person that was incredible. She's like, "You are living with cancer, you are not a cancer patient. We are going to find a way for you to do whatever you're going to do". You know? (Irene Latkjohn)

The overarching theme is that through the support of medical professionals, these participants were able to keep living their everyday lives. This finding suggests that delivering bad news is not the ending point for physicians; extending support and encouragement after the diagnosis was appreciated. However, the support could also come from family members, as this comment demonstrates, *make sure you have a support system...it was a very isolating disease* (Leilani Fields). In all, participants were advocates of having a support system in place after the diagnosis.

In summary, participants commented on life after the diagnosis. The support that was provided to many of the participants by their providers suggest that delivering bad news is not the end point for either party. The providers in this study extended additional support beyond just delivering the bad news, including house calls. Participants reflected on their provider's ability to have them keep living life as normal as possible, such as suggesting ways for running a marathon. Participants were appreciative of these efforts. However, support does not need to just come from the provider as it is important to have a support system in place after the diagnosis for extended care. Table 2 provides a summary of the patient experiences.

Table 2

Summary of findings: Patient experiences

Patient experiences	Sub category	Finding
Before		Feeling “not right”
During	Said (content)	Warning shot
		Lead a prayer
		Directives
		Collaboration Information
	How (relational)	Empathy
	Physician behavior	Kinesics Haptics Chronemics
	Environment	Phone call Face-to-face Both
After		Support

Cultural Responsivity. The second research question asked, what can we learn from these patient stories to inform culturally responsive communication approaches in health contexts? “Culture plays an important role in how individuals see themselves, see others, interpret illness, respond to illness, receive and communicate bad news, and make decisions regarding end-of-life care” (Mitchell, Roth, Basello, & Ring, 2016, p. 339). In the present study, five participants did not specifically mention that culture played a significant role in the delivery of bad news. The comment, *I guess it was just more clinical...there wasn't anything cultural about it* (Leilani Fields) was a common feeling.

⁴However, one participant felt that culture did play a role in the delivery of their bad news and described the interaction with an older male physician as not having a choice, *It's the samurai Japanese male, older, tell you what to do. You do what he says* (William Kapena).

Participants also mentioned that the one communication quality that a health care provider should have is person-centeredness. As one participant explains, each person is unique and health care professionals must be aware of their communication with a patient as a whole person, not just a diagnosis.

It goes back to I think if they really do know me, if they see me in the hall and they talk to me...It really makes a difference. It's like they see you. You have to be a person to a doctor, not a case, not a procedure, not a surgery. When he's in the zone, he's in the zone. I understand that. You still have to be a person to them for them to have that. Not a number, not a medical record. That's what it is. When we become people as opposed to doctor and patient, I think that's when I really start to trust someone. (Anita Jones)

The aforementioned comment echoes a statement made by another participant.

I think it's important for doctors...that you look at a person as a whole being so their emotional and spiritual side, so who they are, and I know that's a lot to ask, but I think it's very, very important that it becomes more of a comprehensive or holistic way to treat patients. (Leilani Fields)

⁴ Although participants mentioned kinesics, haptics, and chronemics—which are aspects of nonverbal communication and intrinsically connected to culture—participants' comments were not directed towards culture specifically. Rather, the comments were more closely related to the behavior of the health care professional.

As with the participant who earlier talked of how the doctor led a prayer immediately following the delivery of bad news, supports a need for individualized communication that had an emotional benefit for the patient, *thinking about it she was crossing a lot of grounds, saying, "Hey, let's pray about this". Then, to me, that showed that she cared about me. That I mattered to her. Because it was personalized.* (Kit Brown)

The value that these participants expressed supports Epner and Baile's (2012) research on patient-centered care. Stepping away from the simplified assumptions based on the patient's ethnicity and nationality is a movement towards a model that represents a more holistic approach to patient care. Communication skills, such as exploration and empathy, are the principles of patient-centered care.

Although participants sometimes mentioned person-centered care, it should be noted that there is overlap between the concepts of person-centered care and patient-centered care. Both paradigms refer to the provider's capacity to address the patient as an individual and provide care in the context of their values and needs. While patient-centered care focuses on the specific communication processes during provider patient interaction, person-centered care goes further to include a more holistic understanding of the relationship through continued care over time (Starfield, 2011; Zhao, Gao, Wang, Lim, & Hao, 2016). In addition, research generally equate patient-centeredness with communication skills (Starfield, 2011). Participants frequently expressed a desire for more individually responsive interactions in the experience of their care delivery, which is most consistent with a description of patient-centered care. Once implemented, these skills could potentially create a pathway to understanding the needs, values, and preferences of each patient (Epner & Baile, 2012).

Patient-centered care is tied to cultural competence. According to Epner and Baile (2012), cultural competence research largely focused on learning the attitudes, values, beliefs, and behaviors of cultural groups; thus, using a categorical approach—a cheat sheet—to learning culture. However, culture comprises multiple variables, affecting all aspects of experience; therefore simplifying culture to a “list of traits” is considerably problematic. Epner and Baile (2012) argue that a cross cultural approach to culturally competent clinical practice focuses on communication skills, awareness of cross-cutting cultural and social issues, and health beliefs that are present in all cultures; thus, patient-centered approach relies on identifying and negotiating different styles of communication.

This idea highlights the recognition of a person’s values in patient-centered care. To obtain a deeper perspective of patient-centered care, the interview questions asked participants to reflect on their personal values. The values mentioned by the participants were faith, making a difference, having balance in life, and reciprocity.

The following excerpt demonstrates this relationship with an example of one participant’s values of faith.

This one lady is sitting down in the X-ray room to do a scan. We were talking and she asked me, "For someone who went through all of this, you look great. You're not sad, you're not fading away. Why is that"? I said, "For number one, it's my faith in the Lord." (Kit Brown)

Participants’ values seem to connect to their vision of quality patient care. In Kit Brown’s case, the physician led a prayer over the phone following the diagnosis. This participant

appreciated this approach because it not only aligned with their value of faith, but the doctor also took the time to understand Kit Brown as a person.

Another example of the relationship between a person's values and of the approach to their health is exemplified through making a difference and improving other lives. For example, one participant mentioned that one of their central values is that the purpose of life is to make other lives better.

It's such things as making a difference in this world. Part of it is it's not just a matter of existing, but making change for the better. Making other people's lives better. It seems weird but that's really what purpose is, purpose in life. (William Kapena)

This same participant felt at ease when the doctor shared a similar reflection about a commitment to make an impact on people's lives. The participant felt more of a connection and greater trust after discovering that the provider shared this common value of helping others, *I felt comfortable...she wanted to make a difference* (William Kapena).

Another participant commented that having balance between the various facets of life, including family, work, and play are crucial to healthy living.

Trying to find a balance between family and work and play because it seems like when those are out of kilter, they're not centered, then I usually get sick or something happens. I think that's real important. I've always really felt that spirituality has, not that I'm very religious, but that there is that relationship that we have with our environment and also how we eat and play. (Kaleo Young)

This personal value of finding balance and interrelationship between various facets of mind, body, spirit and environment, complements a holistic approach to healing. This

participant expressed appreciation for their physician's knowledge in physical and mental well-being, which is aligned with the participant's value of holistic health, *I think for me, a lot of it was that he really educated me about what was happening with my body. It wasn't just the medical side* (Kaleo Young).

In one participant's experience, the provider's communication approach conflicted with one of the patient's values which negatively affected how that communication was perceived. The value of reciprocity, *giving to others and trusting that you'll also be taken care of in return* (Irene Latkjohn) was tied to the expectation of timely communication. Upon reaching out for a second opinion with another doctor, this participant found the delay in receiving information and the lack of responsiveness to violate her value of reciprocity. This was in comparison to her original health care provider who had been more accessible in communication; thus, effectively reflected that value of reciprocity.

The problem was the UCSF [University of California, San Francisco], the people that answer the phones just don't have any information. There's not good networking within their staff whereas here you call Kaiser (in O'ahu), they'll call you back maybe in a couple of hours but they're going to call you back. There, they just never call you back. Never call you back, ever. Even if they would've said, "We don't have it yet." Or "I don't know yet". It just felt like all of my messages were going into a black hole. So just responding back with anything would've been helpful. (Irene Latkjohn)

This finding also emphasizes that a person's values play a role in how the communication is perceived. In the United States, a delay in response can be considered an unequal

relationship or an expression of disrespect. In this case, the participant sees information and communication as a sign of respect, and stressed that responsiveness and an update on the status of the process would have improved the experience even if the results were still delayed.

Participants frequently commented about aspects of their care that either resonated or conflicted with their personal values. This dynamic stresses the significance of patient-centered approaches to care and the impact they have on patient care. This demonstrates the importance of personal and cultural values, and the need for providers to recognize that patient-centeredness is a key dimension of communication skills.

In summary, majority of participants did not indicate that culture was a factor in the delivery of their bad news. However, the findings showed that an attribute that a physician should have is patient-centeredness—a concept that is connected to cultural competence (Epner & Baile, 2012). Participants noted that health care professionals must be aware of their communication with a patient as a whole person, not just a diagnosis. In one example, the participant spoke about how the doctor led a prayer following the bad news. As a result, the participant felt cared for because it was personalized to the participant's religious beliefs. This example demonstrates that communication skills should be linked to the principles of patient-centered care (Starfield, 2011) and provides a gateway to understanding the needs, values, and preferences of each patient (Epner & Baile, 2012).

Recognizing a person's values is a step towards patient-centered care. Values of faith, making a difference, having balance in life, and reciprocity were mentioned by the participants. These values were connected to how they approach their health. This

suggests that patient-centered approaches to care are valuable and contribute greatly to the development of communication skills in health care.

Qualitative Questionnaires

Health Care Professionals. Ten health care professionals completed a brief questionnaire. All were practicing professionals in Hawai'i. Of these, five identified themselves as registered nurses and educators; two as registered nurses; one as the Director/Professor of Nursing, one as an Assistant Professor/Doctor of Nursing Practice student; and one as the Director of Community Partnerships. None of the participants are current colleagues or committee members of mine.

Protocol. Several questionnaires indicated that there was no known protocol and therefore, not used. However, two questionnaires suggested that there was a protocol to follow when bad news had to be delivered by them. One was from an emergency room nurse.

My career was as an ER nurse, so over the years there was a lot of bad news to deliver. The protocol for us was to gather the family into an empty room (with a door) and have the ER doctor and a nurse talk with the family and explain the situation. [Registered nurse (RN), Emergency Room (ER)]

The other comment comes from a labor and delivery nurse.

Usually the MD will talk with patients but occasionally a MD is working...and I will go out to update mother. I try to explain what they may see, what to expect as I always say that they MD will be out to talk with patient as soon as possible. I also try to be with certain MDs while they are talking with some patients. [RN, Labor & Delivery (L&D)]

Research findings about how to break bad news have largely been based on clinical experience and the opinion of experienced medical doctors (Baile et al., 2000; Ptacek & Eberhardt, 1996; see Brewin, 1991). Other research has suggested that health care providers will develop their own guidelines to follow based on reflective practice—a short description might be helpful (see Girgis & Sanson-Fisher, 1998). This may occur because there is minimum curriculum in place for this specific topic. This implies that learning on the job for this particular skill set does occur, which helps to explain the current findings. While several of the narratives indicated that a formal protocol was not known and therefore not used, two narratives—an emergency room nurse and a labor and delivery nurse—expressed that a procedure is followed. These specific nurses are in situations where death and dying often occurs and following a strict procedure could be the result of adhering to the hospital’s policy for such discussions. It could also be the result of real life experiences and their adaptation to the specific environment and situation they are in rather than a result of educational training.

The data also suggest that giving bad news is not the normal scope of the participants practice, as a physician is one to often report the news to the patient, *role of M.D.—he or she may delegate to nurse techs (X Ray, Lab, etc. not to deliver results to patients)*. [RN, Long Term Care (LTC)]. Another participant commented, *in past work experience as a RN, protocols for delivering bad news to patients was taken on by the clinician (physician) whether PCP or specialist involved in the patient's plan of care*. [Assistant Professor, Doctor of Nursing Practice (DNP) student].

According to Dewar’s (2000) research, nurses report that it is the responsibility of the attending medical doctor—or MD—to disclose bad news and RNs know the good and

bad communicators within their purview, *I tend to know which MDs are really good at patient communication and who they don't* (RN, L&D). One participant acknowledged how a known protocol for the delivery of bad news can fall apart in the chaotic environment of an emergency room.

This protocol, however, seems to fall apart many times. One reason is that in the "old days" the family would be in the waiting room. Now, an effort is made to have a family member present even during code situations. This is a good thing, but can become very chaotic in a busy ER. (RN, ER)

In summary, most health care professionals indicated that there was not a known protocol; therefore, one was not used in their practice. Other professionals claimed that there was a procedure to follow, including that it is the physician's responsibility to give the bad news.

Culture. One narrative pointed out that being familiar about the cultural background of a patient would be helpful to their practice, *openly addressing any cultural differences may be necessary to be aware of any preferences for patients, prior to delivering the news to the patient* (Assistant Professor, DNP student). In addition, these participants showed sensitivity to the cultural practices of their patients and appeared open-minded to learning about other cultures.

I strive to learn about other cultures throughout my life and as a big part of caring for others. I seek knowledge about a person's culture so I can care for them; communicate with them as they would like to be/communicated with.

(Director, Professor of Nursing)

Another comment provided support the relationship between culture and delivering bad

news.

I approach every clinical situation differently depending on the individual situation—I've always try to be sensitive to the patient's and family dynamics and feelings. So yes, I would say the patient's culture probably affects the way I deliver the news, but I take every situation on a case-by-case basis. (RN, Assistant Professor)

Specifically, one health care professional participant reported that dynamics of family members was an important consideration of how they communicate such news to the patient.

I always find out who needs to be present (both parents vs. just mom). Some cultures, the father makes all of the decisions so he should be there if giving any news. If it is a culture that is demonstrative, I might make a special effort that they would have plenty of time to react to the bad news (without) being "hurried out" of consultation room. Always give bad news in person, if possible. (Director of Community Partnerships)

Another comment highlighted more examples of how culture is significant to the delivery of the news, *culture plays a HUGE role in how, when, where we deliver "news:" family meeting in private, closed door conference room vs. at the bedside (RN, Critical Care Educator, Staff Nurse).*

Being aware of the cultural background of the patient is considered helpful; thus, health professionals in this study strove to learn about other cultures. Health professionals were mindful of the impact and role of family members.

In summary, participants acknowledged that having familiarity of the patient's

cultural background is helpful in their patient care. They are aware of cultural sensitivity and keeping an open-mind about communication norms and practices of their patients. Health professionals consider family members as an important consideration of how they communicate news to the patients. As such, the role of family members emerged as a consideration for health professionals in the giving of bad news, which is consistent with research (Rollins & Hauck, 2015).

Experience. Health professionals report that patients' behavior and reaction when receiving the bad news is unpredictable, such as this narrative explains.

You never knew how someone will react. Some people just say ok and walk out, some people scream and cry. I've had a spouse hug me and then started to pound me in the chest. So I let her until she was done. Be prepared for anything. (RN, ER)

This thought is aligned with current research. For example, nurses report that they are ill prepared to answer questions that come from their patients and family members (Dewar, 2000). Although this respondent seemed to handle the intensity of the patient's response, it is not uncommon for some nurses to feel like a failure in these situations (Warnock et al., 2010). One narrative highlights a specific experience in giving bad news.

I have had experience delivering bad news in the intensive care unit. I remember a specific instance in which I had to encourage a husband to talk with the physicians about his wife's condition explaining her vital signs trends, change in level of consciousness and other signs of physiological determination. He cried. But I think it helped him come to realize that maybe his wife was not going to get better and come home. (RN, Assistant Professor)

The aforementioned narrative describes the difficult but necessary practice of utilizing good communication skills to deliver bad news. In this specific case, the patient's husband was able to obtain a realistic view of the poor prognosis due to effective communication that was provided by the health care professional. In other cases, while the desire to communicate well is present, the message may not be received in the same way that it was intended. In other words, what is sent is not always received. As a result, miscommunication can occur. This complexity of communication is clearly illustrated in the following narrative, *I later found out that the family had a very different understanding...to the information than I thought they had* (RN, L&D). This type of situation may occur because of the type of information presented. Due to the potential life changing news, the patient and family members may be too overwhelmed to adequately process the information given by the health care professional and may turn to another provider to restate the original message. This is often the case for nurses; after the news is given by the physician, the nurse may have to clarify the news to the patient and/or family members due to the complexity of the information (Dewar, 2000).

Health care professionals expressed tips that they have created and used in their practice due to their experience to help build understanding.

As a bedside clinician for 25 years, I have developed "key phrases" to use depending on the religious beliefs, socio-economic status, [and] education level of the family/patient. I always speak honestly. I always speak to the education level of the pt. [patient]/family. I use "therapeutic touch" and "listening" strategies with my clients. I always start with, "What is your expectation of this hospitalization"? Then we discuss PHM [past medical history], A&P [assessment

and physical], pharma [medications] ...pain and emotional status. Always speak honestly, professionally and if you cannot answer their questions...NEVER make up date, lie. Bring in your MD. (RN, Critical Care Educate, Staff Nurse)

The tips suggested by this health care professional supports research in best practices.

First, asking the patient, *what is your expectation of this hospitalization?* is similar to the recommendation presented in the SPIKES model (Baile et al., 2000), which encourages providers to ask what patients have been told about their medical situation and condition.

The purpose of this step is to assess the patient's perception of what is already known.

Most times I sit with the patient and their family. I start off by some silence, I talk about the bad news—slowly. Then I pause and then start with an open question, or a comment like, "I know that this is not what you had hoped for..." Pause. It is sometimes just holding the person's hand and not saying anything for awhile-- "being with, being present, caring". (Director, Professor of Nursing)

As with this health care professional, providing a warning statement, such as *I know that this is not what you had hoped for* as described in the narrative is also aligned with Baile et al.'s (2000) recommendations. A warning potentially lessens the impact of the bad news and helps to avoid abrupt communication.

Be clear as possible; No medical jargon; Plan time to listen, answer questions and plan a time to return for more questions after family has had time to think about the news; bring tissues; it is okay to cry and hug. (Director of Community Partnerships)

Baile and colleagues (2000) also suggest avoiding jargon. However, one discrepancy between these findings and the literature centers on the use of haptics (touch) when

providers communicated bad news to a patient. As stated in the literature, a small percentage of patients would like the doctor to touch their hands or shoulders during the delivery of bad news (Furjimori et al., 2007), and two of the narratives recommend using touch (e.g. *holding the person's hand, hug*) during this type of transaction. It is also suggested in previous recommendations to touch the patient when communicating bad news (Baile et al., 2000; Girgis & Sanson-Fisher, 1998; Ptacek & Eberhardt, 1996).

In summary, health professionals report that patients' behavior and reaction when receiving the bad news is unpredictable. Due to years of experience health professionals offered tips that they have created and used in their practice, many of which are aligned with research (see Baile et al., 2000).

Educators Support. Narratives from the health care professionals expressed the desire for more education and curriculum enhancements, *ensure that it is a part of educational curricula towards the end of a program and clinical education towards the end of a program* (RN, Assistant Professor). Another comment was more specific, *ethics classes, religious classes, state board of nursing, mandating CE's [or CEU, continuing education] on "Death," "Active Patient Deaths" "Death and Dying," "Terminal patient/family care"* (RN, Critical Care Educate, Staff Nurse).

Another important consideration is the expansion of curriculum inclusions of communication skills for the development of health care professionals. Through educational training, a variety of approaches could be used. One participant talked of a teaching strategy called Simulation-based Immersive Medical (SIM) training, *I think situation training may be useful to allow providers to interact during scenarios. SIM training along with a more traditional approach (using previously developed education*

models) be the way to go (Assistant Professor, DNP student). Another participant discussed teaching through role play, *role playing is good, especially with a good actor being the grieving family member—its good practice to know when to touch and when to just stand there* (RN, ER). Observing others in practice through a multidiscipline approach was another participant suggestion, *observing real "bad news" giving conversations is also helpful. It is useful to see how different disciplines and different clinicians give bad news* (Director of Community Partnerships).

SIM is considered to be a useful and helpful mode of instruction for communication skill training in medical and nursing schools (Wakefield, Cooke & Boggis, 2003). In addition, Little and Bolick (2013) encourages incorporating role playing scenarios and group discussions into training, both for pre-licensure and graduate nursing students, as these exercises better prepare them for future clinical conversations. Furthermore, one way of learning how to break bad news is through observing other physicians. Colletti et al.'s (2000) research note that it is typical to have physician learn about this process through observing more senior physicians. In Garg et al.'s (1997) study, of the medical school students who had seen clinicians performing this task, seventy five percent (75%) reported that they saw what they considered a good example of how to break bad news.

In summary, health professionals expressed the desire for more education and curriculum inclusions on the giving of bad news and suggested using a variety of instructional approaches such as SIM, role play, and observation.

Nursing Students. Fifteen questionnaires were distributed to nursing students. Five questionnaires were from students who were recent graduates of the Hawai`i

Community College License Practical Nurse (LPN) program and were currently enrolled in prerequisites courses to be eligible for the fall 2018 UHH school of nursing program. Ten questionnaires were from third year nursing students, who are set to graduate in spring 2018. All were current students at UHH. UHH was selected as the place of data collection as I am a current instructor at this university. Some of my students are subsequently admitted into the UHH school of nursing program. However, none of the respondents in this study were current students of mine.

Protocol. One theme from the narratives indicated that they were unsure of the protocol for giving bad news. Other responses provided guesses, but were uncertain what the current protocol was such as this comment, *unsure of current protocol. I would assume one would want to gather all pertinent information...treatment options, and deliver the news to the patient in person.* (Current BSN student, #8). Another participant echoed the previous comment, *not sure...If there was no protocol, I would be honest, frank, and empathetic* (Current BSN student, #11). An additional comment provides support for this finding, *don't know...guess: sit down, make sure client has time, provide for privacy, use therapeutic communication skills.* (Current BSN student, #12)

In their questionnaires, nursing students did not indicate if they were going to learn about guidelines for delivering bad news in a future class. However, suggestions of what they thought they should do were aligned with research about patient preferences. First, *deliver the news to the patient in person* is what most patients prefer (Fujimori et al., 2007; Schofield et al., 2001). Similarly, *should be delivered in a calm environment* and *provide for privacy* are aligned with the SPIKES model (Baile et al., 2000) of arranging a private space to deliver the bad news.

Questionnaires also indicated that the protocol should first determine the nature of bad news that has to be delivered, *the protocol for delivering bad news to patient is to determine first what kind of news it is; certain news is only for doctors to give* (Recent LPN graduate, #2). Another comment elaborates on this process, as some news or results should be communicated by the attending physician.

I believe the protocol for delivering bad news is structured upon the depth of news such as a diagnosis of cancer is for the doctor to tell the patient. In other news such as you're pregnant is delivered after a pregnancy test and blood test to confirm. The nurse then delivers the news and provides resources and continued plan of care. (Recent LPN graduate, #3)

Similar to what is reflected in the literature, student nurses, like health professionals, reported that physicians' are responsible to break bad news to patients.

In summary, nursing students indicated that they were unsure of the protocol for giving bad news. However, they provided "how to" suggestions and tips which complemented literature on patient preferences. Nursing students also believe that some news or results should only be communicated by the physician.

Culture. Narratives demonstrated that they had a sense of cultural awareness and its impact on the communication process, such as this comment explains, *profoundly; nurse needs to have knowledge of cultural norms, ethics, values, customs in order to appropriately and effectively deliver news* (Current BSN student, #12). Another comment considers culture an important factor in patient care in the delivering of bad news.

Patient culture makes a major difference on how you deliver news...It is important to take their culture into consideration, so you don't offend the patient.

Also, knowing a patient's culture can help you as a nurse understand their responses or reactions. (Current BSN student, #15)

Being sensitive to other cultures and of their beliefs are crucial to meet the needs of the patient as this comment reflects, *the nurse must be sensitive towards the clients beliefs and practices in order to provide holistic and culturally congruent care* (Current BSN student, #6). To this end, student nurses provided several examples of how culture could impact the giving of bad news. One comment describes the impact of family members and the amount of information shared.

Culture could influence who they want with them when news is delivered; who they want to hear the news from; whether or not they want to hear the news at all; how they respond to the news (openly distraught, privately, etc.); how much information you give to the patient initially vs. waiting to deliver treatment plans. (Current BSN student, #8)

Several comments were directed to culture in general, such as *some cultures do not like direct eye contact. Some cultures need their husbands to be there.* (Recent LPN graduate, #3). Another comment echoed this, *some cultures are more stoic than others, while others are more sentimental—this is a big factor to consider when preparing to deliver bad news.* (Current BSN student, #5). Another comment was more specific and included an example of information sharing, *culture may impose limitations on disclosing information to the client. Some cultures may believe in the preservation of hope over complete veracity.* (Current BSN student, #6). However, one comment was specific to Middle Eastern cultures, *in many Middle Eastern cultures, you direct the news to the male and not the female even if the female is the patient directly influenced by the news*

(Current BSN student, #13).

In summary, nursing students consistently identified the impact that culture has on communicating bad news and provided concrete examples of how culture directly affects the delivery of bad news.

Experience. Although most of the narratives indicated no prior experience on breaking bad news, some of the respondents reflected on what should be done and offered tips on how to handle the situation as this comment explains, *It is important to allow the individual and/ or their family to grieve appropriately, in a way that they may gain closure* (Recent LPN graduate, #5).

One participant provided a tip list to keep in mind.

Try to keep patients well informed throughout the process; Meet their level of openness; Offer sincere sense of "being sorry" for their bad news; Be there for questions; Be a continued presence—check in with patient; Be calm, supportive, open, show concern. (Current BSN student, #8)

Another comment reflected on tips that were developed in practice.

This is a time to just sit quietly as a medical professional, and allow silence. Some patients [take] in the information, and just wants someone to sit next to them during this time. I have learned to allow the patient to express themselves without opinions or reassurance, and do not force them to express themselves until they are ready to communicate. (Recent LPN graduate, #1)

One comment provided tips specific to Hawai`i's context.

Here in Hawaii, it seems if you use the direct approach, it could be considered as being rude so I would probably take things really slow and explain the situation

as they are ready to hear it, put my hand in theirs. I would be very sensitive to reactions and give a hug if needed. Offer any help I am qualified for and offer other agencies services where applicable. (Current BSN student, #7)

Participants' suggestions reflect research based best practices. First, *give a hug if needed* as pointed out in one narrative is a recommended communication skill (Baile et al., 2000; Girgis & Sanson-Fisher, 1998; Ptacek & Eberhardt, 1996), although some patients do not want to be touched during this type of situation (Furjimori et al., 2007). This same narrative would also *offer other agencies services where applicable* to the patient. According to Girgis & Sanson-Fisher (1998), providers should present information about the availability of support services, such as hospice and counseling. Third, demonstrate empathy. As one narrative explains, *offer sincere sense of "being sorry" for their bad news* is aligned with Girgis & Sanson-Fisher (1998) research.

One tip was a reflection on how the respondent would like to receive the news, *I have delivered and received bad news. I appreciate a compassionate, well informed, direct approach myself, and so try to give it the same way* (Current BSN student, #14). This nursing student's narrative highlights empathy. How the news is delivered is based on this person's view of how they would like to receive it themselves if they were the patient. This student understands how it would feel to be a patient in this type of situation. Interestingly, using a *direct approach* as suggested by this student narrative is in contrast to another student narrative that points out that using a direct approach is considered rude. This difference of opinion is reflected in speech act theory (Austin, 1962; Searle, 1981). Explicit—or direct—speech acts can be interpreted as rude and manipulative; whereas indirect speech acts express messages in a roundabout way

leaving room for miscommunication to occur. This emphasizes the fact that communication is complex.

Three participants who had delivered bad news shared their experience. One comment provided a specific example of the type of bad news that was delivered, *telling family members of grandmother's declining health condition*. (Current BSN student, #6) Another participant shared multiple examples of the variety of bad news that was given.

When I worked as a homebirth midwife, I had to deliver bad news on a number of occasions. The "news" included miscarriage, fetal abnormalities, incompatible with life, genetic disorders, and when a woman or baby had to be transferred from home to the hospital because of various complications. (Recent LPN graduate, #8)

The third narrative described the process—as a nurse—of sharing the news.

I am present in the room when the doctor communicates the bad news to the patient. In my experience, 75% of the time the patient will nod and state they have no questions or concerns when communicating to the physician. Once the physician leaves the room, they will ask what the physician just explained to them again (and sometimes in a simpler form). I have noticed patients will ask or discuss their concerns with bad news more with individuals they trust or familiar with on a daily basis (which is usually the nurses, if they are living in long term care). The other 25% of the time, patients and family members are in shock. (Recent LPN graduate, #1)

These narratives reinforce the fact that nursing students are involved in the process of breaking bad news. The final narrative in particular shares an insight of, *once the*

physician leaves the room, they will ask what the physician just explained to them again (and sometimes in a simpler form). This reflection is related to what was previously discussed; nurses are sometimes asked by the patient and/or family members to clarify what the doctor said (Dewar, 2000).

In summary, most of the nursing students indicated no prior experience on breaking bad news. Those who had experience informed patients of a miscarriage or family members of their loved ones declining health status. Some of the respondents reflected on the interaction and provided suggestions and tips on how to handle the situation,

Educators Support. The majority of responses indicated that more education/course offerings in a variety of communication skills is needed. In particular, learning about different cultures and their style of communicating was the most frequent response. The following quote captured this insight, *in-depth look at how cultures communicate with each other as well as those outside their culture. Give tools to use for specific cultures in the community* (Current BSN student, #11). More specifically, one comment suggested to include nonverbal communication in culture training, *I think it is important for educators to include culture, tone, facial expression teaching in their training* (Current BSN student, #15). Other comments focused on learning about patients' possible reactions, such as *Provide education on the different reactions a patient can have and how to handle each reaction* (Current BSN student, #10). Another quote supports learning about patient reactions, *it is important to include training on how to react to and interact with certain types of reactions that can occur while giving bad news.* (Current BSN student, #15)

Similarly, there was a request from students to learn how to be competent in their own delivery.

Teach the learners to look for possible "red flags" which would indicate it is not the right time to deliver the news...teach the learners to look for subtle cues which determine the "right" time to deliver bad news and try to determine if its better when fam[ily] are present. (Current BSN student #10)

This competence included how to initiate and end a difficult conversation, *would be helpful to include ideas about ways to start and stop a conversation that includes bad news* (Current BSN student, #15).

Other comments included using SIM, role playing, and having health professionals discuss their personal experiences as instructional methods. The value of SIM and role playing have been previously researched through systematic literature reviews (Cant & Cooper, 2010). Having providers share their personal experiences demonstrates empathy, which is reflected in literature as a recommended way to communicate bad news (Baile et al., 2000).

In summary, similar to health professionals, nursing students suggested that there is a need for more communication skill based education and course offerings.

Specifically, nursing students wanted to learn more about how different cultures communicate. In addition, they wanted to learn how to be more competent in their own communication. They also indicated modes of instruction, including SIM, role playing and sharing experiences, as ways of learning that would be helpful to their training.

Cross Analysis. A cross analysis was used to determine if there were any gaps and/or overlaps between the perspectives of health care professionals and nursing

students. Each group of participants provided answers to the same questions in a written format, as described above.

Protocol. Both health professionals and nursing students mention that delivering bad news is the physician's responsibility. Most health professionals report that there is not an established protocol to deliver bad news to patients. On the other hand, most nursing students were not sure if there was a protocol to follow.

Culture. Both health professionals and nursing students expressed similar perspectives regarding culture and giving bad news. Both groups recognize that cultural differences impact communicating with patients. Health professionals stated that they strove to learn about others while providing care. In this respect, they presented as open-mindedness to the cultural perspectives of their patients. In addition, they appeared sensitive to others, including to family dynamics, as this is an important consideration of how they communicate such news to the patient. On the other hand, nursing students provided more specific, concrete examples of how culture directly affects the delivery of bad news, such as the amount of eye contact and who is present in the patient's room.

Experience. Health professionals and nursing students both state tips for how to deliver bad news to patients. Although a variety of suggestions were provided by both groups, three recommendations overlapped: use touch (i.e. hold hand, hug), not rushing, and allow silence.

As explained in their questionnaire, the recommendations from health professionals stem from their years of experience. This was not the case for nursing students, as the majority of respondents reported not having any experience of delivering bad news in practice.

Educators Support. Health professionals and nursing students both agree that more education and curriculum development in delivering bad news is needed. Both groups mention that SIMS training and role playing are ways to instruct this area of content. Professionals and students differ in what to include in the instruction. One narrative from a health professional stated that a course in death and dying, for example, would be beneficial for students. However, nursing students wanted to learn about how different cultures communicate, including how various cultures respond to unfavorable information. In addition, students would like to learn how to be competent in their communication, such as when to begin and end this type of conversation. Health professionals did not mention this area for instruction in delivering bad news. Overall, the narratives from health professionals focused on the modes of instruction (SIMS, role playing, etc.) while the narratives from nursing students provided insight into the specific content (e.g. cultural differences) that they wanted to learn more about. Table 3 provides an overview of these findings.

Table 3

Summary of findings: Health care professionals and nursing students

	Protocol	Culture	Experience	Education
Health care professionals	Not known/not used	Yes; Helpful to know patients' cultural background	Unpredictable	More education needed
	Physicians' responsibility	Considers the role of family members	Provided tips and suggestions	Suggested modes of instruction (SIM, role play, observation)
Nursing students	Unsure	Yes; Provided examples how culture impacts (e.g. eye contact)	Most had no experience	More education needed
	Physicians' responsibility		Provided tips and suggestions	Suggested content focused curriculum of learning culture

Summary

In summary, of those who were diagnosis with a chronic disease diagnosis, most acknowledged and appreciated the empathy that their provider gave. An overarching theme is that participants also support a focused, patient based method to delivering the news. In addition, participants' approach to health care was linked to their personal and cultural values. Health care professionals and nursing students had little training for delivering bad news. Both agreed that more education in this area is needed.

Chapter Five

Discussion

In reviewing the experiences of patients receiving bad news, one major theme was their appreciation of empathy exhibited by their health care professional. Another theme was that a person's values, which are closely connected to culture, were connected to their approach to health care. Health care professionals and nursing students had little training for effectively delivering bad news, and both agreed that more education in this area was needed.

The following discussion begins with focusing on two different communication characteristics—empathy and values—that reflect patient-centered care. Recommendations for health care educators and providers follow. I then provide insight into the experience and training of health care professionals and nursing students. Limitations of this study and future research suggestions are described. To conclude, I reflect on this research project in the context of my next professional step and my dad's story.

Patient Perspective: Patient-Centered Communication Skills Needed

By analyzing an individual's experience and perception of receiving bad news diagnosis of a chronic disease from their physician, I sought to identify ways to improve communication skills with health care professionals. From this study, it is evident that support for more instruction in patient-centered communication training is needed in the educating of future health care providers. In this study, half of the participants who were diagnosed with a chronic disease noted that health care professionals must be aware of their communication with a patient as a whole person, not just a diagnosis. The following

discussion provides insight into the patient-centered communication skills that patients encourage health care providers to have when disclosing bad news of a chronic disease.

Empathy. This research recognizes how individuals who have been diagnosed with a chronic disease process that information in stages: before, during, and after the news. From this process, the concept of empathy emerged as an important and significant factor of patient-centered communication, especially during the diagnosis.

One way to achieve patient-centered care is through communicating empathy. Empathy was displayed as a communication competency that affected trust and comfort. In this study, when the physicians self-disclosed about their own family members to their patients, it served as a base for establishing common ground. This allowed the participants to feel more comfortable communicating about a sensitive topic with their provider. Participants appreciated this expression of compassion in their care. This is one example of how empathy could impact the communication process and provides evidence that this communication skill and competency should be included in medical curriculum. However, it is noted in research that empathy declines the further one progresses in medical training.

Many students enter medical and nursing school with the intention of serving others. Kuriakose, Revankar, Viveka, Shetty, and Rao's (2015) study, conducted in India, determined that serving humanity, especially the underserved (i.e. poor and needy), was the main motivational factor for first year students entering medical school. Other factors included the view that medical doctors are a respected profession in society, having 'Dr.' in prefix, and wearing a stethoscope. This is a similar finding in Nepal, where serving the sick, personal interest, and social prestige were the most

significant factors influencing the decision to attend medical school (Hayes & Shakya, 2013). However, through the process of attending medical school and obtaining traditional clinical training, students are reported to have an increased cynicism (Testerman, Morton, Loo, Worthley, & Lamberton, 1996) and a decrease in empathy (Hojat et al., 2009; Neumann et al., 2011; Newton, Barber, Clardy, Cleveland, & O'sullivan, 2008). Nursing students are similar. Wilkes, Cowin, & Johnson's (2014) study, conducted in Australia, points out that many enter the field for the ability to help others and that nursing is a stable career. A decrease in empathy has been shown in nursing students while attending nursing school (Ward, Cody, Schaal, & Hojat, 2012).

Based on the work of Kopelman (1983) and Testerman et al. (1996), Batley, Nasreddine, Chami, Zebian, Bachir, and Abbas (2016) defines cynicism as the “tendency to doubt and disbelieve the sincerity of strong moral principles and motives” (p. 2). Through a process termed “traumatic de-idealization” (Kay, 1990), Testerman and colleagues (1996) argue that medical students develop cynicism as a result of their experiences while attending medical school. A classic review of the literature suggests that medical school environment is conducive to producing cynicism, regardless of participation in old or new curriculum (Rezler, 1974). This may occur for a variety of reasons including mastering scientific material, experiencing stressful initial encounters with patients, and having limited energy for being compassionate to patients, even though reminded to do so by others (Eron, 1958; Kopeland, 1983). The struggle of balancing these overwhelming experiences as a medical student may lead some to develop and use cynicism as a coping mechanism in response to their stressful environment (Eron, 1958; Testerman et al., 1996).

Cynicism could lead to a decrease in empathy (Batley et al., 2016). To determine when, if any, changes in students' empathy occurred during medical school, Hojat et al. (2009) conducted a longitudinal study. Over four hundred students completed an empathy scale at five different times throughout the course of their medical school studies. It was determined that empathy decreases in the third year of medical school. Ironically, this is typically when students begin clinical work. Positive feelings of medicine was also shown to decrease in the third year of Malawi medical school students (Wendland & Bandawe, 2007). An updated literature review also supports that empathy declines during medical school (Neumann et al., 2011). Similarly, Ward et al. (2012) conducted a study to examine changes in nursing students' empathy while in nursing school. Findings suggest that like medical students, empathy also declines in nursing students when they start working with patients.

In general, a decrease in empathy during medical training may occur due to a variety of reasons. These factors include stress, anxiety, and pressure to do well in a highly competitive academic curriculum (Newton et al., 2008). Lack of role models coupled with negative attitudes from others in the profession may also play a role (Hojat et al., 2009). These factors may lead to burnout, reduced quality of life, and depression (Neumann et al., 2011). Neumann and colleagues (2011) add that exposure to taboo topics, such as morbidity, mortality, and end of life care, causes students "to suffer more from distress themselves; thus they become unable to provide rational health care or protect themselves by dehumanizing patients" (p. 999); thus, leading to a decline in empathy in patient care.

These are important considerations that could affect communication and patient care. Students who enter school with compassion, sincerity, and positivity, may develop cynical attitudes as they progress through their educational training (Eron, 1958). This could impact effective communication skills and competencies and practices such as empathy. As noted in research, this shift ironically occurs when students are traditionally exposed to clinical practice of working with patients.

This cynicism is especially significant due to the prevalence of chronic diseases in Hawai'i. As such, it is likely these future health professionals will be required to work with patients who will need to not only be told of their diagnosis, but will be in need of continued care and support. Yet, previous research dating back forty years has found that medical interns lacked concern for chronically ill patients (see Kutner, 1978). Fitzpatrick et al. (1993) suggested that first year medical students had positive attitudes toward chronically ill patients, but developed negative attitudes during clinical training. Not all research aligns with this. Using a mixed method approach of interviews and questionnaires of medical students, Turner, Pugh, and Budiani (2005) found that students enter medical school with more negative thoughts (long-running, incurable, life altering, and terminal) about chronic disease patients than previously noted in research. These negative thoughts may impact effective communication with patients.

Although students enter medical school with compassion, sincerity, and positivity, empathy typically declines as they proceed through medical school. As a profession providing care to others at their most vulnerable time, this is considerably problematic. To maintain a sense of empathy throughout their medical or nursing education, the

following recommendation is for health care educators: Health care educators need to develop a longitudinal communication skills based intervention for medical instruction.

Turner et al. (2005) encourages medical schools to continue to search for and include training programs that highlight the rewards and challenges of treating and communicating with chronically ill patients. One step to address this need is to include instruction on empathy. However, can empathy be cultivated successfully in medical education? A review by Batt-Rawden, Chisolm, Anton, and Flickinger (2013) says it can be—with the right interventions. Successful interventions of patient narrative and creative art (creative writing, blogging, drama, poetry, fiction and film); communication skills (coaching on formulating empathic phrases and conveying empathy verbally and nonverbally); interpersonal skills training (lecture then role playing); patient interview (students visit chronically ill patients in their homes); and experiential training (SIM training) have been shown to increase empathy in medical students (Batt-Rawden et al., 2013).

Of these, my recommended intervention would be the patient interview. The patient interview intervention requires students to conduct home visits with chronically ill patients; these have shown to have increase empathy (Mullen, Nicolson, & Cotton, 2010; Yuen et al., 2006). Students should be aware of the patient perspective and be exposed early to the emotions of those they may one day treat. Students who would like to honor the patient voice may interview someone who is going through or has gone through a chronic disease. This is an important component to consider as students will learn more about the patient perspective—an attribute that they may not discover until late in their training when they start working directly with patients. In turn, this may help students

gain insight into what patients go through while receiving care. My hope is that students remember patients, their stories, and remain compassionate throughout their educational journey and practice. This learning process will not only allow students to learn another side of medicine through the voices and eyes of a professional provider and of a patient, but develop/continue empathy based on their experience with their interviewee.

Cultural Responsivity. Culture, health, and the individual are interconnected. Mitchell et al.'s (2016) research suggests that culture shapes self-concept. This may inform individuals of how to view and respond to illness, receive and communicate bad news, and make end-of-life decisions. Much research on culturally responsive care in the delivery of bad news focused on race and ethnicity as a proxy for understanding communication preferences. As previously discussed, this is troublesome. Hawai'i is comprised of multiple ethnicities, races, and cultural backgrounds. To limit such research to just ethnicities as a unit of measure is inadequate. Epner and Baile (2012) argues that culturally competent clinical practice focuses on communication skills, awareness of cross-cutting cultural and social issues, and health beliefs that are present in all cultures. Therefore, a patient-centered approach identifies and negotiates styles of communication, including, but not limited to, decision-making preferences, roles of family, and mistrust (Epner & Baile, 2012). This view of the individual supports the need for patient-centered care.

Although the majority of participants in this study did not indicate that culture was a factor in their experience of bad news, one participant noted that culture played a powerful role in their interaction with their provider. In this specific case, there was no

discussion of care. Rather, the participant did what the doctor said to do because it was culturally expected as a means of demonstrating respect.

However, culture can have a strong influence on values. Therefore, one way to increase patient-centered care, thus engage in culturally responsive care, is to recognize a person's values. A person's personal and/ or cultural values guide their approach to health care. This study suggests that when providers learn about the person and develop relationships with their patients, it provides a richer and deeper understanding of why their patient may feel and communicate the way they do. It also could provide insight into patient satisfaction. In turn, this builds capacity for trust and rapport between the parties. This was the case for one participant who recounted the time that her provider led a prayer immediately following the diagnosis. The provider acknowledged her patient's religious practices, a value of the participant, and initiated a response that was perceived as comforting. By recognizing this specific value, patient-centered care was established.

Although previous research focused on race and ethnicity for patient preferences in the delivery of bad news, this can be problematic because of the diversity that is represented in Hawai'i. However, one way to promote patient-centered care that embodies cultural responsiveness is by examining a person's values. A person's values influences their approach to health care.

The following recommendation is provided for health care providers specifically, but could be broaden to educators as a tool for instruction and discussion: Health care providers need to include a personal and cultural value questionnaire in patient medical history forms. Examples of these questions include, how do your personal and cultural

values influence and impact the way you communicate and view health care? How do you prefer to communicate with your provider?

Medical forms are part of the intake experience of being a patient. As such, they are part of a patient's medical ritual. The forms are confidential and provide a safe place for sharing history. In turn, the provider could review the patient's responses with the patient during their medical interview. This form can be updated as often as necessary. Including these types of questions may counteract the power imbalance of traditional short and to the point medical interviews. In this way, the provider has a conversational starter to inquire and learn more about their patient, thus cultivating a patient-centered approach to health and healing. Learning about a person's values does take more time as this is an inquisitive approach, but the outcome can increase trust and satisfaction in the patient-provider relationship.

Based on cultural responsiveness, another recommendation is geared for health care educators: Health care educators need to develop a cultural exchange program. One way to increase cultural understanding is through travel, which provides a foundation for learning how different cultures communicate (Jacobs, Stegmann, & Siebeck, 2014). Medical and nursing students should be encouraged to take a semester off to travel and study abroad in another country or in a different community from their own. This experience would be slightly different than the required residency or internship program, which is typically focused in clinical settings and held towards the latter part of their training. In this case, students would be encouraged to learn about cultural practices, rules, and norms from members of the community who are not in clinical practice, in addition to completing mandatory classroom and clinical hours. In other words, the

teachers are people from the community of which they are a part (Jacobs et al., 2014).

This program would be encouraged throughout; therefore, students could participate in any point in their medical or nursing schooling. This platform would provide a rich and deep understanding and appreciation of culture, nonverbal communication (including kinesics, haptics, and chronemics), and in people.

Health Care Professionals and Nursing Students: Experience and Education

Experience. Health professionals report that patients' behavior and reaction when receiving the bad news is unpredictable. Patients may be too overwhelmed to understand the life changing information and may turn to another provider (e.g. a nurse) to restate or clarify what the doctor said. In one specific instance, the husband of a patient was able to realistically comprehend the poor prognosis of his wife, because of the health care professional's skills in communicating the information. While this interaction suggests the use of effective communication was successful, it is not always the case in every scenario—miscommunication does occur. As such, the message may not be received in the same way as the way it was intended.

Despite having varied experiences, health professionals report that there was not a known protocol; therefore, one was not used in their practice. Other professionals claimed that there was a procedure to follow, but this occurred with an emergency room nurse and a labor and delivery nurse. Although a formal protocol is not common, these two particular examples suggest that following a strict procedure could be the result of adhering to the hospital's policy. It could also be the result of adaptation of real life experiences and not necessarily a result of educational training. Health practitioners will often develop their own guidelines to follow based on reflective practice (see Girgis &

Sanson-Fisher, 1998). Health professionals also shared that it was the physician's responsibility to give the bad news. This could be interpreted as the following the protocol of hierarchy in medical communication.

From their years of experience, health care professionals offered tips that they have created and used in their practice, including asking the patient what their expectation is of the office visit, stating comforting messages, and using appropriate touch. These types of statements and behavior may help to build understanding, brace the patient for news to follow, and open the opportunity for dialogue.

Most of the nursing students indicated no prior experience on breaking bad news. However, it is evident that student nurses play a big role in delivering bad news. Several narratives reflected their experience, such as informing patients of a miscarriage or informing family members of their loved ones declining health status. On occasion, the student was the one to repeat or clarify what the doctor said. Therefore, nurses become the original messengers of the bad news (Dewar, 2000).

Nursing students indicated that they were unsure of the protocol for giving bad news. Other participant responses provided guesses, but were uncertain of any existing protocol. However, the suggestions provided by the nursing students, such as deliver in person and arrange for patient privacy, complemented literature on patient preferences. Nursing students also pointed out that the protocol should first determine what kind of bad news has to be delivered. It is their belief that some news or results should only be by the physician. This is aligned with research (Dewar, 2000).

Despite this, some of the nursing students reflected on the interaction and offered tips on how to handle the situation, such as giving a hug, offering additional services

where applicable, and showing empathy. One narrative discussed giving the news in a way that was reflective of how they would like to receive it themselves in a similar situation, which is a reflection of empathy.

Education. Health professionals expressed the desire for more education and curriculum inclusions on giving bad news. Through educational training, a variety of approaches could be used including SIM, role play, and observation. Research supports these modes of instruction for medical education.

Similar to health professionals, nursing students suggested that there is a need for more communication skill based education and course offerings. However, nursing students specifically wanted to learn about different cultures and responsive ways of communicating across these differences. Students also wanted more insight into how to be competent in their own communication style, such as when to start and stop communication episodes. Other participant narratives suggested to have course instruction via SIM, role playing, and having health professionals share their personal experiences.

In general, how to deliver bad news is a guessing game for the medical professional community. Even with research and published guidelines available, most health care professionals shared that they were not aware of a communication strategy in place—and many nursing students indicated they were unsure if there was one. Given this, it is not surprising to find that both groups—health care professionals and nursing students—stress the need and demand for structured instruction and training that help to develop and refine communication skills. Interestingly, health care professionals thought about the mode of instruction (e.g. SIM), whereas nursing students wanted concrete

information about culture responsiveness when communicating bad news. This difference of opinion could impact instruction, as educators may be missing out on what students really need to learn.

The following recommendation is provided for health care educators: Health care educators need to develop a discussion program with an experienced provider for student learning. This recommendation calls for health care educators to set up a discussion program where a provider and a group of students are matched up by medical interest and interact—separate from class sessions. The purpose is have to providers share their professional experiences as a way to learn about “what really happens.” Opposed to classroom guest speakers, these hour-long monthly sessions during the four years of medical or two years of nursing education would focus on the provider’s professional experience of ethics, family, and cultural issues of delivering bad news in health care. At the conclusion of each discussion, students would share their thoughts through personal writing, or journal entries. Stevens and Cooper (2009) point out that, “writing decreases stress and improves health” (p. 15), especially to those that, “write regularly about troubling or traumatic events in their lives” (p.15). These writings would serve as a vehicle for self-expression, to not only process what really happens in medical cases, but to actively reflect as a future health practitioner. Below is a sample step by step classroom guide for these sessions.

- Provider provides a scenario based on their professional experience
- Provider poses questions to the students related to the scenario
- Students write thoughts/comments
- Students gather and share their opinions in a small peer group

- Provider comments on each opinion
- Provider provides what she/he actually did in the situation and shares insights
- Discuss results and ethics of the case as a class
- Students reflect on their response in comparison the providers response in a journal entry (this is not to say that the provider’s handling was appropriate—rather, the journal entry is simply a reflective process)

Although there is no substitute for experience, a student can learn a lot from the stories and perspectives of health care professionals in the field. These discussions allow a safe place where topics that are usually considered taboo are examined, which may foster critical, creative, empathetic and reflective thinking. They also serve as a reminder of the messiness of real life, while keeping students “human” in their thought process. What makes these discussions different than traditional classroom guest speakers or from M&M conferences⁵ is due to the longevity, small group sharing, and reflective thinking via journal entries that takes place. My hope is that students will become more prepared for handling difficult scenarios when they arise due to the mentorship and reflections they experience and potentially internalize as a result of these curricular interventions.

Limitations

This study has several limitations. First, the sample size of chronic disease patients for this study is considerably small. This occurred because participants were difficult to find who were willing to participate in the study. Although using social media and snowballing techniques were used (the latter garnered most participants), this

⁵ The goal of M&M conferences is “to derive knowledge and insight from surgical errors” (Mitchell et al., 2012, p. 26)

resulted in few participants. Several potential participants were approached by me, but chose not to participate; while others initially agreed to be interviewed, but withdrew. This resulted in interviewing only six participants. This difficulty suggests that using social media to initially recruit patients for a sensitive topic may not to be the most appropriate method of recruitment. One reason is because potential participants may not want to broadcast their health conditions in a public forum. Another reason is because the topic itself—health—is a personal matter. Social media does not carry the same interpersonal weight as face-to-face interactions do. Initial face-to-face interactions, such as an orientation session given at a health clinic or hospital, might have clarified the scope of the project better. In addition, the six participants comprised of five females and one male of varying ages, three of which had cancer conditions as their chronic disease. This gender imbalance combined with the lack of varying chronic diseases, does not adequately address these populations. In addition, medical doctors or medical school students did not participate in this study. They play an intricate role in delivering bad news. Other members in the medical community, such those included in the study, often refer to the physician for this task. Therefore, these professionals and students would have provided more insight in addition to those who provided the narratives in this study.

Another limitation of this study is that the participants were asked to give retrospective accounts of their experience of being diagnosed or their experience of delivering bad news. This is limiting for several reasons. Participants could forget to include information that could be important and relevant to the study. In addition, discussing a topic in this way triggers thoughts from memory; thus, participants could potentially think of their experience differently when it occurred. Since the interviews or

narratives did not occur immediately after the experience, collecting retrospective accounts may not accurately portray the experience. All of these factors contribute to the limitation of the present study.

Future Studies

Future studies could explore several areas. First, to increase validity of the results, more participants who were diagnosed with a chronic disease need to be interviewed. Due to the small sample size, emerging themes were limited to just a few areas. This was not particularly troublesome for this study as it is meant to capture individual voices. However, more research is needed if one is to widen the results. Do the themes identified by this initial study hold consistently with a wider sample?

Second, a better understanding of what is considered good communication in health contexts need to be examined. It is evident that some nursing students and health professionals had differing opinions and experiences of delivering bad news. By first asking what is “good” communication in a health context, we can then ask; Does the provider’s perception of what is “good” communication change over time, and with experience? Examining these opinions and experiences over a period of time could determine if individual perspectives and communication skills change with added experiences.

Finally, how people feel about communicating about health could be another future study. What are individuals’ perceptions about communicating and exploring their health? Participants were difficult to obtain for this study. The researcher found that several potential participants decided to not follow through with the interview—even after initially agreeing to it—because they did not want to relive the experience. This

could be due to the newness of the diagnosis and/or difficulty of having a chronic condition in the first place. Similar to the previous recommendation, examining a disease from a new diagnosis to recurrence diagnosis could help in gaining perspective of how the news could be impactful over time. In addition, embarrassment, sensitivity, and face-saving strategies (see Goffman, 1955) about personal health issues could be explored.

Reflections

As I reflect on this journey, I have grown as an individual, an educator, and a research practitioner. My appreciation for the medical community intensified as a result of this project. Being a health care provider is not an easy task. They subject themselves with years of schooling and training and often face difficult situations, as part of their desire to help others. Questionnaires from the health care professionals were especially awakening for me because it reminded me that they are human. As I read through the questionnaires, I began to empathize with them. Some did not have any instruction on what to do when faced with delivering bad news, and in one case was the subject of a chest pounding. Yet health care providers are expected to remain competent, professional, and calm. Patients may blame the giver of the news, but health care providers seem to be doing their best with what is known. However, I still believe that communication can always be improved.

Second, I come away with a better understanding of the patient experience. Although my dad's story highlighted the dynamics of communication in a highly emotional context, not every health journey is experienced this way. What we perceive as *good communication* can occur, even in difficult situations. A profound example of this is when a participant in this study described how after learning the diagnosis, her doctor led

a prayer over the phone. The participant was appreciative of this effort. This example stuck with me because I did not expect the doctor to be that attuned and emotional cognizant of the participant's values, nor switch and separate science from emotions and faith in one phone call. Not only did this example remind me to recognize my own biases, but is also reminded me how important it is to slow down and pause from the world around us. We can connect, relate, and inspire others by communicating—with others.

My overall goal is to become a leader in health communication education and recommend changes to improve the programs in our health systems for the state of Hawai'i. My desire is to build capacity for more patient-centered communication skills among health care providers and educational institutions. Working to reduce disparities and help all people achieve quality health, or health equity, especially in vulnerable or culturally isolated communities, is a growing concern. This research project reinforces my desire to continue to provide support for both patients and practitioners. I have learned—again—that communication plays a key role in how we shape our understanding of important events that occur in our lives.

Through my capacity as an educator, this dissertation serves as a stepping-stone for my future work. How I can be of service to others is by providing more education in communication skills to prepare our future health care leaders and providers. Inspired by individual stories, one step to narrow the patient-provider gap is to introduce new curriculum.

Next step: Applied health communication course. As a health communication educator, I see value in updating and adjusting curriculum to meet student needs. In the course that I created and still teach, Communication 241, students not only share their

stories and experiences of health care, but also learn about practical skills such as Health Maintenance Organization (HMO) compared to Preferred Provider Organization (PPO) and advance care directives compared to living wills. One goal of my class is to have students leave the course well informed to make empowered health care decisions.

Based on this research, what is needed at my educational institution is an applied health communication course that is focused on developing patient-centered communication skills for future health care providers, especially for pre-nursing majors. The focus of this course would be to enhance students' patient-centered communication skills and competencies, specifically in regards to empathy and cultural responsiveness. By actively applying these principles, the instruction would include role playing and in-class discussion sessions, with experienced providers, as recommended by the participants in this study.

My hope is that I am able to develop leaders and health care professionals with improved communication skills and cultural competence. In turn, these professionals can serve their communities in Hawai'i better and represent their community more effectively within the health and education sectors.

Concluding thoughts: My dad's story. This year, 2017, marks my dad's passing of sixteen years. It was a very difficult experience and I still carry it with me today. I believe the doctors did everything they could, which is what my mom pleaded for. I can say now that I would have asked the doctors more questions, but I do not know if that would have changed anything about his prognosis and treatment plan.

I never expected to become a patient advocate, but I can attest that life experiences can ultimately direct your journey. For me, studying health communication is

a way of honoring my dad—I can let others hear and learn from what he went through, and how it impacted us as a family. Although there are many stories out there like his, this paper represents a hopeful future. We know that disease is not going to go away, but we can change what happens when it does occur. My hope is that research, education, narratives, and storytelling in health continues, as we still have a lot to learn from those who live it.

Appendix A



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Office of Research Compliance
Human Studies Program

TO: Twomey, Sarah, Curriculum Studies, University of Hawaii at Manoa
FROM: Lin-deshetler, Denise, Dir, Human Stds Prog, Social & Behavioral
PROTOCOL TITLE: Developing Communication Competencies in the Giving of Bad News
FUNDING SOURCE: NONE
PROTOCOL NUMBER: 2016-30074
APPROVAL PERIOD: Approval Date: August 11, 2016 Expiration Date: August 10, 2017

NOTICE OF APPROVAL FOR HUMAN RESEARCH

Under an expedited review procedure, the research project identified above was approved for one year on August 11, 2016 by the University of Hawaii Institutional Review Board (UH IRB). The application qualified for expedited review under CFR 46.110 and 21 CFR 56.110, Category 6, 7b.

This memorandum is your record of the IRB approval of this study. Please maintain it with your study records.

The UH IRB approval for this project will expire on August 10, 2017. If you expect your project to continue beyond this date, you must submit an application for renewal of this Human Studies Program approval. The Human Studies Program approval must be maintained for the entire term of your project.

If, during the course of your project, you intend to make changes to this study, you must obtain approval from the Human Studies Program prior to implementing any changes. If an Unanticipated Problem occurs during the course of the study, you must notify the Human Studies Program within 24 hours of knowledge of the problem. A formal report must be submitted to the Human Studies Program within 10 days. The definition of "Unanticipated Problem" may be found at the HSP Policies & Guidance website, www.hawaii.edu/researchcompliance/policies-guidance, and the report form may be downloaded from the website www.hawaii.edu/researchcompliance/report-protocol-violation-or-unanticipated-problem.

You are required to maintain complete records pertaining to the use of humans as participants in your research. This includes all information or materials conveyed to and received from participants as well as signed consent forms, data, analyses, and results. These records must be maintained for at least three years following project completion or termination, and they are subject to inspection and review by the Human Studies Program and other authorized agencies.

Please notify this office when your project is complete. Upon notification, we will close our files pertaining to your project. Reactivation of the Human Studies Program approval will require a new Human Studies Program application.

Please contact this office if you have any questions or require assistance. We appreciate your cooperation, and wish you success with your research.

1960 East-West Road
Biomedical Sciences Building B104
Honolulu, Hawaii 96822
Telephone: (808) 956-5007
Fax: (808) 956-8683
An Equal Opportunity/Affirmative Action Institution

Appendix B

University of Hawai'i at Mānoa Consent to Participate in Research Project

Developing Communication Competencies in the Giving of Bad News [Interview]

My name is Rayna Morel and I am a graduate student at the University of Hawaii at Mānoa in the College of Education, Professional Doctorate in Educational Practice Program. As part of the requirements for earning my graduate degree, I am conducting a research project. The purpose of my project is to learn about how health care providers can improve their communication skills when delivering bad news about a person's health.

Activities and Time Commitment: If you participate in this project, I will meet individually with you for an interview at a location and time convenient for you. The interview will consist of approximately fifteen (15) open ended questions and it will take up to 90 minutes. A second (or third) interview of the same time length may be necessary. Interview questions will include questions like, "How did the doctor inform you about your diagnosis? Describe what that experience was like for you. How did the news affect/impact you?" will be asked. Only you and I will be present during the interview. I will audio-record the interview with multiple recording devices (placed in front of you) so that I can later transcribe the interview and analyze the responses. You will be one of about ten (10) people whom I will interview for this study.

Benefits and Risks: There will be no direct benefit to you for participating in this interview. There is potential risk of psychological pain as you recall your experience. You may also stop the interview, take a break, or withdraw from the study completely at any time in the process. I also have counseling resources that I will provide at the interview. The knowledge gained from this research may contribute to curriculum development for my own communications courses and for medical training programs and schools.

Privacy and Confidentiality: I will keep all information in a safe place. Only my University of Hawai'i advisor and I will have access to the information. The University of Hawai'i Human Studies Program has the right to review research records for this study. Once the interview has been transcribed, I will erase or destroy the audio-recordings. When I report the results of my research project, I will not use your name nor use any other personal identifying information that can identify you. I will use pseudonyms (fake names) and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law.

Voluntary Participation: Your participation in this project is completely voluntary. You may stop participating at any time. If you stop being in the study, there will be no penalty or loss of benefits to you.

You will receive a \$5 gift card to either Starbucks or Jamba Juice for your time and effort in participating in this research project.

Appendix B (cont.)

Questions: If you have any questions about this study, please call or email me at (808) 960-9811 or raynam@hawaii.edu. You may also contact my adviser, Dr. Sarah Twomey, at (808) 956-5898 or twomey@hawaii.edu. If you have questions about your rights as a research participant, you may contact the UH Human Studies Program at (808) 956-5007 or uhirb@hawaii.edu.

Please keep the section above for your records.
If you consent to be in this project, please sign the signature section below and return it to the researcher, Rayna Morel.

Tear or cut here

Signatures for Consent

I, _____ give permission to join the research project entitled, *Developing Communication Competencies in the Giving of Bad News*. I have read and understand the project information provided on page 1. I understand that I am free to change my mind about participating at any time and may withdraw my consent and discontinue participating by notifying the researcher.

Name of Participant (Print): _____

Participant's Signature: _____

Signature of the Person Obtaining Consent: _____

Date: _____

Appendix B (cont.)

University of Hawai'i at Mānoa Consent to Participate in Research Project

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Activities and Time Commitment: If you decide to participate in this project, you will be asked to fill out a brief questionnaire. The questionnaire will consist of a few demographic questions and open ended questions. It should take approximately 15 minutes to complete. You will be one of about twenty (20) people who will complete a questionnaire for this study.

Benefits and Risks: There will be no direct benefit to you for participating in this questionnaire. However, you may experience a benefit in describing your experience. The knowledge gained from this research may also contribute to curriculum development for my own communications courses and for medical training programs and schools.

Privacy and Confidentiality: I will keep all information in a safe place. Only my University of Hawai'i advisor and I will have access to the information. The University of Hawai'i Human Studies Program has the right to review research records for this study. Once the interview has been transcribed, I will erase or destroy the audio-recordings. When I report the results of my research project, I will not use your name nor use any other personal identifying information that can identify you. I will use pseudonyms (fake names) and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law.

Voluntary Participation: Your participation in this project is completely voluntary. You may stop participating at any time. If you stop being in the study, there will be no penalty or loss of benefits to you.

You will receive a \$5 gift card to either Starbucks or Jamba Juice for your time and effort in participating in this research project.

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Name of Participant (Print): _____

Participant's Signature: _____

Signature of the Person Obtaining Consent: _____

Date: _____

Appendix B (cont.)

CONFIDENTIALITY

CARE Hawaii is committed to maintaining the privacy, and understands the importance of, safeguarding the client's personal health information. We are required by Federal Law to maintain the privacy of health information that identifies you or that could be used to identify you. Information regarding your health care is protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). We will not use or disclose personal health information without consent, except as described in our Notice of Privacy Practices.

NON-DISCRIMINATION

No one shall be excluded from or be denied access to services only because of his/her race, color, age, sex, physical or mental handicap, religious creed, national origin, or political beliefs.

CARE Hawaii, Inc.
100 Apōke St.
Hilo, Hawaii 96720

Crisis Services



East Hawaii
CMO/CSM/LCRS
100 Apōke St.
Hilo, Hawaii 96720

This program is funded by the State of Hawaii,
Adult Mental Health Division.

CMO Services

Crisis Mobile Outreach (CMO) is a community-based service for clients experiencing a crisis situation. The program aims to assist individuals with the potential for danger to themselves or others and their support systems with the goal of constructively resolving aspects that may have precipitated the crisis. CMO supports clients by providing accessible, responsive, coordinated, and timely community assistance.

Services provided include: risk assessment, clinical assessment, crisis shelter assessment, crisis stabilization, crisis intervention, planning, transportation, and short-term treatment which includes, but is not limited to, medication administration or arrangements, consultations, and referrals and linkage for follow up care.

CMO Services are face-to-face crisis stabilization, provided 24 hours a day, 7 days a week, and responded to within 45 minutes or less.

CARE Hawaii provides Crisis Services on the islands of Oahu, Hawaii and Kauai.

CSM Services

Crisis support management (CSM) is a time-limited support service intended for individuals who are in crisis, who are not linked, or who do not have an appropriate Division case manager.

Services provided by the CSM Team include: stabilization of crisis situations; initiation of treatment interventions; resolution of problems and conflicts; coordination with other agencies; assisting the consumer in gaining access to necessary services through linkage and assistance in returning to their pre-crisis status; linkage with Division designated case managers as needed; and arrangement for ongoing support and treatment.

The goals of CSM services include, but are not limited to, assisting frequent users of crisis services with plans of more intensive interventions for behavior that could further disrupt community integration and returning the consumer to pre-crisis life.

CSM Services are available 24 hours a day, 7 days a week.

Crisis Services are accessed through the State of Hawaii Adult Mental Health Division Crisis Line of Hawaii:

1-800-753-6879 (Toll Free)

LCRS Services

Licensed Crisis Residential Services (LCRS) are provided to assist individuals with the potential for danger to self or others and their significant support systems in constructively resolving situations which may have precipitated the crisis by providing a community service which is accessible, responsive, coordinated, and timely. The emphasis is to keep the individual safe in a least restrictive setting so that the individual can cope with difficult personal situations.

LCRS offers short-term, acute residential services to individuals experiencing crisis, or a period of acute stress that significantly impairs the capacity to cope with normal life circumstances. The LCRS Program provides services that address the psychiatric, psychological and behavioral health needs.

The goals of LCRS include, but are not limited to, assisting frequent users of crisis services with plans of more intensive interventions for behavior that could further disrupt community integration and returning the individual to pre-crisis life.

LCRS provides accessibility and availability to psychiatric services 24 hours a day for assessment, treatment, and consultations.

Appendix B (cont.)



The flyer is a yellow rectangular graphic with a white horizontal band in the middle. On the left side, there are three logos: the University of Hawaii Hilo logo, the University of Hawaii Hawaii Community College logo, and the UH Hilo Division of Student Affairs logo. The main text is in bold black font, with a tagline in italics and a bulleted list of services. The bottom section of the flyer contains a paragraph of text about the location and hours of the counseling services.


UNIVERSITY
of HAWAII
HILO


UNIVERSITY of HAWAII
HAWAII
COMMUNITY COLLEGE


UH HILO
DIVISION OF
STUDENT
AFFAIRS

Counseling Services

Because everyone needs help sometimes.

- Personal counseling
- Self-development
- Support through difficult times

Free to UH Hilo & Hawaii CC Students

Located on the 2nd floor of the Student Services Building. Open 8am to 4:30pm. Monday to Friday. Call **932-7465** to set up an appointment. For after hours or holiday crisis support call the Suicide Prevention Line at **1-800-273-8255**. For emergencies you may call **911** or go to the nearest emergency room.

Appendix C

[Facebook Post]

Recruitment Script for Participants that have been Diagnosis with a Chronic Illness

Hello everyone,

My name is Rayna Morel and I am a graduate student at the University of Hawaii at Mānoa in the College of Education, Professional Doctorate in Educational Practice Program. As part of the requirements for earning my graduate degree, I am conducting a research project. The purpose of my project is to learn about how health care providers can improve their communication skills when delivering bad news about a person's health.

If you have received a chronic disease diagnosis (e.g. Cancer, Type 2 diabetes) from your physician at least once in your adulthood years, you are eligible to partake in this project. If you decide to participate in this project, I will meet individually with you for an interview at a location and time convenient for you. The interview will consist of approximately fifteen (15) open ended questions and it will take up to 90 minutes. A second (or third) interview of the same time length may be necessary. Interview questions will include questions like, "How did the doctor inform you about your diagnosis? Describe what that experience was like for you. How did the news affect/impact you?" will be asked. Only you and I will be present during the interview. I will audio-record the interview with multiple recording devices (placed in front of you) so that I can later transcribe the interview and analyze the responses.

Benefits and Risks: There will be no direct benefit to you for participating in this interview. However, you may experience a benefit in describing your experience. The knowledge gained from this research may also contribute to curriculum development for my own communication courses and for medical training programs and schools.

If you have any questions or would like to participate in the research, I can be reached at raynam@hawaii.edu

Appendix C (cont.)

[Facebook Post]

Recruitment Script for Health Care Professionals and Nursing Students

Hello everyone,

My name is Rayna Morel and I am a graduate student at the University of Hawaii at Mānoa in the College of Education, Professional Doctorate in Educational Practice Program. As part of the requirements for earning my graduate degree, I am conducting a research project. The purpose of my project is to learn about how health care providers can improve their communication skills when delivering bad news about a person's health.

If you are a health care professional or a current nursing student living in the State of Hawai'i, you are eligible to partake in this project. If you decide to participate in this project, you will be asked to fill out a brief questionnaire that would be sent via email in MS Word format. The questionnaire will consist of a few demographic questions and open ended questions. It should take approximately 15 minutes to complete.

Benefits and Risks: There will be no direct benefit to you for participating in this interview. However, you may experience a benefit in describing your experience. The knowledge gained from this research may also contribute to curriculum development for my own communications courses and for medical training programs and schools.

If you have any questions or would like to participate in the research, I can be reached at *raynam@hawaii.edu*

Appendix D

University of Hawai`i at Mānoa

Developing Communication Competencies in the Giving of Bad News

Researcher: Rayna Morel

ORAL SCRIPT FOR INTERVIEWS

Aloha, Mahalo for agreeing to participate in my research project. My name is Rayna Morel and I am a graduate student at the University of Hawaii at Mānoa in the College of Education, Professional Doctorate in Educational Practice Program. As part of the requirements for earning my graduate degree, I am conducting a research project. The purpose of my project is to learn about how health care providers can improve their communication skills when delivering bad news about a person's health

This qualitative interview will take approximately 90 minutes. I will be using multiple audio recorders to ensure your proper collection of your voice. The audio recording devices will be placed in front of you. I will run through a series of questions on a sheet that is provided to you. I expect that even with a list of questions, the interview will be free-flowing and conversational. My intent is to capture the details of your experience as a patient who received a chronic diagnosis. I may request a few follow up interviews with you if there is a need to gather more information.

After the interview is complete, it will be transcribed into a written record. You will receive a copy of the transcription for your review and may make any changes you wish. All information will be documented and analyzed into a dissertation that will be provided to the University of Hawai`i at Mānoa to satisfy my doctoral program requirements.

Benefits and Risks: There will be no direct benefit to you for participating in this interview. However, you may experience a benefit in describing your experience. The knowledge gained from this research may also contribute to curriculum development for my own communication courses and for medical training programs and schools.

I understand that this topic may be difficult to discuss emotionally. If you should become uncomfortable during this interview, we can take a break, skip the question, or stop the interview. You can withdrawal from this research project at any time from the project altogether by notifying me. Please note that counseling is available. For University of Hawai`i at Hilo (UHH) and Hawai`i Community College students, you may obtain free counseling services on the UHH campus. A business card with contact information will be provided to you at the conclusion of the interview. Counseling is also available through Crisis Services from the CARE Hawai`i Inc., located in Hilo. A brochure with further information and contact information will be provided to you at the conclusion of the interview.

Appendix D (cont.)

Are there any questions that I can answer before we start?

Let's begin.

Conduct Interview

Thank you again for your time today.

INTERVIEW QUESTIONS

Background/Culture

1. Could you tell me about yourself? (Your family and where you are from and grew up, etc.)
2. What values and practices are important to you in your life?
3. How many languages do you speak? Which one are you most comfortable using?
4. What is your earliest memory of going to the doctor?

Area: What kind of communication was used?

1. Tell me your story about your illness.
2. How was it diagnosed?
3. How did your doctor tell you this news?

Area: What was the quality of the communication?

1. How did the doctor inform you about your diagnosis?
2. Describe what that experience was like for you.
3. How did the news affect/impact you?
4. Could you describe any disconnect you experienced between the communication style of your health care provider and your own communication style?
5. Describe any cultural differences/difficulties you experienced in the communication of your diagnosis.
6. If you were to assume the role of the physician, how would you deliver such news? In other words, if you could deliver such news, like yours, what would you say to the patient?
7. Is there anything you think doctors could do better of when delivering bad news?
8. Was there anything that you thought was missing from that medical communication?
9. What did you find most challenging about that specific visit?
10. What did you find to be most uplifting about that specific visit?
11. How satisfied were you with your physician's communication when he/she delivered this news?
12. Is there anything else that you would like to share?

Appendix D (cont.)

Questionnaire for Health Care Professionals

Thank you for agreeing to participate in this questionnaire. As indicated in the consent form, any information that you provide may be used in my research and writing. However, any identifying information will be kept confidential. During the questionnaire, if you do become stressed or uncomfortable, you can skip the question or take a break. You can also stop the questionnaire or withdraw from the project altogether.

Please return this questionnaire via email to: raynam@hawaii.edu.

Directions: Please answer the questions below. Feel free to use the back of this paper if necessary.

Professional Role / Title: _____

Years of experience in this role: _____

Medical / Nursing / Other school attended: _____

1. What is the current protocol for delivering bad news to patients?
2. How does the patient's culture impact the way you deliver the news?
3. What has been your experience in communicating bad news?
4. How might educators support training in this area?

Appendix D (cont.)

Questionnaire for Nursing Students

Thank you for agreeing to participate in this questionnaire. As indicated in the consent form, any information that you provide may be used in my research and writing. However, any identifying information will be kept confidential. During the questionnaire, if you do become stressed or uncomfortable, you can skip the question or take a break. You can also stop the questionnaire or withdraw from the project altogether.

Please return this questionnaire via email to: raynam@hawaii.edu.

Directions: Please answer the questions below. Feel free to use the back of this paper if necessary.

What is your degree seeking program? _____

What year are in (e.g. second) and when is your expected graduation date? _____

What nursing school are your currently attending? _____

1. What is the current protocol for delivering bad news to patients?
2. How does the patient's culture impact the way you deliver the news?
3. What has been your experience in communicating bad news?
4. How might educators support training in this area?

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