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Student Healthcare Providers' Illness Narratives: Impact on Family-Focused Care

Lindsey Ann Lawson

LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Faculty of Graduate Studies

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by

Lindsey Ann Lawson

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

_____, Chairperson
Carmen Knudson-Martin, Professor of Counseling and Family Sciences

_____
Barbara Hernandez, Director of Physician Vitality, Professor of Medical Education, School of Medicine

_____
Winetta Oloo, Assistant Professor of Counseling and Family Sciences

_____
Jackie Williams-Reade, Assistant Professor of Counseling and Family Sciences

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ABSTRACT OF THE DISSERTATION

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Doctor of Philosophy, Graduate Program in Marital and Family Therapy
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Dr. Carmen Knudson-Martin, Chairperson

In this study, we interviewed 30 students training for three areas of healthcare: medicine, nursing, and medical family therapy (MedFT). Through grounded theory analysis of these interviews, we looked to understand how these providers connected their own experiences with illness to their clinical work, particularly in including patients' family members in care. The majority of participants, and especially those in medicine and nursing disciplines, described a tension between their desire to connect with patients and families and their developing definition of professionalism. For others, the impact of students' personal experiences with illness seemed to provide a different definition of professionalism, making these personal connections more purposeful.

We found that students described four significant processes around a core category of defining professionalism: (1) facing discrepancies between ideals around being a healthcare provider and students' lived experiences, (2) coping with the challenges of healthcare culture, (3) navigating relationships between own experiences with illness and patients' experiences, and (4) attempting to connect more closely with patients and their families. Implications suggest that training programs across disciplines consider how to support self-of-the-provider reflection, relational perspectives of illness, and students' abilities to connect with patients and include families in care.

Keywords: medical family therapy, illness narratives, collaborative care, family-centered care.

CHAPTER ONE

INTRODUCTION

Illness narratives, or the way that people organize around the experience of illness, give insight into how people make meaning of their lives (Werner, Isaksen, & Malterud, 2004; Marshall, Bell, & Moules, 2010; Wright & Bell, 2009). Sharing of narratives creates connection between our own experiences and others' (Schwind, 2003) and is a confirmation to both listener and speaker that the narrator will continue to live and tell his or her story (Monks, 2000). The experience of sharing is a recursive one which trains both parties in the process of thoughtful, healing reflection (Schwind, 2003). Illness narratives have been studied and documented in a variety of settings and with multiple populations (Charon, 2006; McDaniel, Hepworth, & Doherty, 2003; Wright & Bell, 2009); however, the research does not extend to their impact on healthcare providers' professional lives and the likelihood that they will include patients' families in care.

In the proposed dissertation, I will use social constructionist and narrative theory frameworks to study the relationship between healthcare students' awareness of their own personal illness narratives and the impact on the way that they approach inclusion of patients' family members in care. This will be accomplished by developing grounded theory based on interviews with students from three sample groups, including nursing, medicine, and medical family therapy. Information from this study will provide healthcare educators with a better understanding of the relationship between students' own experiences and the care that students give to patients and their family members.

Background

There is a growing body of research that suggests that the experience of illness is felt by more than just the individual patient, but by family members as well (Martire, 2005; Marshall, Bell, & Moules, 2010). This challenges the culture of individuality around illness, and instead suggests that "relational suffering" (Marshall, Bell, & Moules, 2010) impacts not just the individual but larger systems as well, including family members, the community, and healthcare providers. Nonetheless, the idea of individually-experienced illness is reflected in training programs for healthcare providers and may keep many from being aware of the relational or systemic impact of illness for both themselves and patients and their families. For example, training programs for healthcare professionals tend not to support self-reflection or vulnerability in students (McDaniel, Hepworth, & Doherty, 1992), and clinical practice values include the ability to remain "objective", or to not be overly influenced by patients' experiences of illness, and to maintain a safe distance between one's professional and personal life (Weingarten, 2010).

Failure to take a relationally-focused view of illness can have a negative impact on the quality of care given to patients and their families. Research shows that families who are included in care feel more supported and tend to have better relationships with one another (Martire, 2005). In addition, patients consistently demonstrate better outcomes when the strengths of families are utilized to help support them (Hopkinson, Brown, Okamoto, & Addington-Hall, 2012; Marriott, Donaldson, Tarrier, & Burns, 2000). While there is clear evidence that family-focused care can be beneficial for all involved, this does not often translate into actual practice (Borins, Holzapfel, Tudiver, &

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Bader, 2007). An obstacle to providers connecting with patients and their families may

be heightened reactivity to what patients are experiencing or how they are behaving, and

it makes sense that this reactivity may be connected to providers' personal experiences.

These unspoken and often unrecognized relationships between providers and the families

they work with likely impact the quality of care patients receive.

Power differences between provider and patient may also contribute to difficulties

providers may have connecting relationally with patients and their families. The standard

for relationships between patients and providers has been slow to change from a

traditional, hierarchical relationship to a more collaborative one. Partnership

relationships in which power is shared more equally between provider and patient are

often seen as "too simplistic" or "immature" (Hook, 2006). The use of power *over*

patients can be damaging, and may be difficult to combat, as it is often disguised as being

"helpful" (McDaniel & Hepworth, 1999). A solution to the problem of imbalanced power

is shared power, or collaboration between provider and patient (Gallant, Beaulieu, &

Carnevale, 2002; McDaniel & Hepworth, 1999). This may be accomplished in part by

providers' sharing of illness narratives which puts them in a more vulnerable place and

may help them experience patients with increased empathy.

Medical family therapists use a systemic, biopsychosocial framework to work

collaboratively with patients and other healthcare disciplines (Tyndall, Hodgson,

Lamson, White, & Knight, 2012), and are in a unique position to help link theory to

practice and providers to patients and their families. They have the opportunity to sit

with families for significantly more time than other healthcare providers have available to

them, and can strategically share pieces of contextual information with providers to help

them experience patients and their families in a different, more empathetic way. In addition, medical family therapists may talk briefly with physicians and nurses about their experiences with patients, normalizing frustrations and gently suggesting modified ways of interacting or communicating with patients. While we are learning more about the role that medical family therapists have in working with patients' families, we still know little about how healthcare providers' own experiences impact their interactions with patients and whether or not they involve family members in care.

Objectives

The overall aim of this dissertation study is to develop grounded theory that explains how healthcare providers' reflections on their illness narratives impact their experiences in providing family-centered care in the workplace. Research from this study is expected to produce one publishable paper that will address the following three aspects of the illness narratives of medical, nursing, and medical family therapy students:

Research Question 1: How do illness narratives and personal histories impact the way that healthcare providers include patients' family members in care?

Research Question 2: How do illness narratives and personal histories relate to providers' attitudes towards other healthcare disciplines and/or collaboration?

Research Question 3: How do illness narratives and personal histories influence relational practices with patients (i.e., "bedside manner") and clinical choices across disciplines?

Rationale

There is clear evidence in the literature of the importance of providing family-focused care, yet these ideas do not seem to be translating into providers' actual clinical work. These include the benefits of self-reflectiveness for healthcare providers around the impact of illness (Monks, 2000; Schwind, 2003; Werner, Isaksen, & Malterud, 2004), and the inclusion of families of patients in care (Doherty & Campbell, 1998; McDaniel, Hepworth, & Doherty, 1992). These areas may be closely connected, as additional research shows that the ability to self-reflect may promote increased empathy (Erlingsson, 2009). For example, those students who have connected with their own experiences of loss – either their own or that of a family member or close friend – may be better able to connect with patients and to see the impact of illness and hospitalization on patients' families as well.

This study will do several things to address this gap between providers' own experiences with illness and a more systemic understanding of their patients' experiences. It will shed light on how different training programs across disciplines address self-of-the-provider issues and link this to how families are incorporated into care given to patients. In addition, this research will inform medical family therapists on how training impacts providers' relationships with patients and their families and may also foster better collaboration between disciplines. Lastly, this study may also help to decrease power differentials between patient and provider and increase empathy towards patients and family members as providers show vulnerability in reflecting on their own experiences with illness.

CHAPTER TWO

CONCEPTUAL FRAMEWORK

As a field, family therapy is set apart from other disciplines because of the special attention paid to relational systems. In this study, I will use systems theory as an overarching framework, and will be additionally informed by social constructionist and narrative theory orientations. The chapter begins with a definition of a systemic view of healthcare, highlighting the role that medical family therapists can take in helping to bridge different levels of the healthcare system. In addition, the social construction of important themes in healthcare, such as value around individualism and impact to patient care, will be discussed. It concludes with a discussion of how both narrative and social constructionist theories emphasize a relational, rather than individual approach, fitting well with the overall aim of this study to understand how providers' illness narratives impact the delivery of services to patients and their families.

A Systems View of Healthcare

A systems theory perspective of healthcare may be defined as the process of, "forging collaborative relationships between families and communities and community organizations that serve families (Doherty & McDaniel, 2010, p. 6)." This fits well with how medical family therapists work, often finding themselves as the "bridge" between different levels of systems: individuals, families, communities, and the healthcare system. Systemic-thinking medical family therapists may conduct therapy sessions with patients and their families, offer suggestions to help them navigate the medical system, communicate patient needs to healthcare staff, and gently offer suggestions on how

providers can modify interactions with patients to improve care and outcomes.

In a qualitative text analysis of fifteen medical family therapy casebook articles published in *Families, Systems, and Health* between 1996 and 2007, researchers Bischoff, Springer, Felix, and Hollist (2011) found that medical family therapists take a systemic approach to healthcare by understanding and valuing patients' multisystemic experiences with illness (including the impact to family members), creating caring relationships with patients, and helping increase respect on multiple levels of the healthcare team for the patient and his or her voice. This systemic view of healthcare differs significantly from a traditional view in which providers take an expert role with patients, and family members may be seen as obstacles.

A systemic view of healthcare fits well with the two theoretical frameworks that will be used for this study: social constructionism and narrative theory. These frameworks overlap significantly, and there are common points in each that support providers taking a more relational approach towards conceptualizing illness and including families in care. Concepts in both social constructionism and narrative theory include the individualistic approach to healthcare in the United States as a social construction, and the value of an inclusive and relational "we" approach (or multistoried approach) to illness, and personal and professional identities as multifaceted. In the following, I outline these main tenets of social constructionist and narrative theories and address how they fit with the proposed study.

Social Constructionist Theory

The social constructionist movement began as a result of postmodern thinking in

Western culture after the Enlightenment and brought about significant changes in the ways that we view truth, reality, science, and reason (Gergen, 2009). In particular, three shifts in thinking provided a foundation for social constructionism: awareness of how values impact what we believe to be true, the values held in language and the problems with reason, and exploration of the ways that society impacts scientific knowledge (Gergen, 2009). While social constructionism was heavily influenced by the postmodern critique of modernism, the process shifted from a critique only towards the goal of creativity, or "generative theory" (Gergen, 2009). Rather than simply challenge the assumptions of the time, social constructionist thinkers want their readers to do more: they want them to use this new awareness to bring about positive social change.

Narrative Theory

In their development of narrative theory during the 1980's, social workers Michael White and David Epstein (1990) continued to build on a social constructionist framework towards a unique, post-structuralist way of understanding people. Up until this time, therapy had been dominated by psychological theory and practice, in which therapists were seen as experts and few questioned socially accepted truths or assumptions. Inspired by disciplines of cultural anthropology, feminism, social justice, and queer studies, White and Epstein began to take into account the impact of this larger social context that seemed to strongly dictate how people saw themselves (Madigan, 2010). They suggested that, rather there being certain "truths" about people waiting to be discovered, it was possible to have multiple ways to view people, the cause of problems,

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and the path toward solutions. These were strong challenges to deeply held ideas around therapy, and they continue to influence postmodern therapists today.

Application of Frameworks to Healthcare

Relational Approach to Illness

Social constructionist and narrative ideas translate to the world of healthcare in a number of different ways. The United States typifies an exceptionally individualist culture, which can easily leave people feeling isolated, misunderstood, and distrusting of relationships with others (Gergen, 2009). This mentality gives providers an individualistic way of understanding problems as well: they may see problems (whether physical, emotional, relational, or spiritual) as belonging to one person only (Gergen, 2009). For example, a woman suffering from diabetes is labeled a "diabetic." The problem is likely seen as her "responsibility," and as something that she – and she alone – should have prevented or at least managed. She may be seen as "getting what she deserves," and little consideration will likely be given to the impact this diagnosis has on her relationships, her family, or her community.

Social constructionist and narrative perspectives counter this individualistic perspective of illness. Madigan (2010) writes that at its core, narrative theory goes against this individualistic view of people and their relationships, and instead takes a stand that it is *only* through relationships that people can be understood and supported. In accordance with its social constructionist roots, this narrative viewpoint goes against an individualistic culture, especially within the medical setting that can often be quick to label and diagnose. Taking a social constructionist, relational "we" approach to illness

(Knudson-Martin & Silverstein, 2009; Marshall, Bell, & Moules, 2010; Wright & Bell, 2009,) can move healthcare professionals from seeing people as diseases, to viewing families and communities as being both impacted by illness and a source of healing.

Developing Professional and Personal Identities

Over the past several decades, understanding about the development of professional and personal identities has shifted from belief in separate, contained identities towards a more multi-faceted approach (Kram, Wasserman, & Yip, 2012). Underlying our identities are constantly-developing values, goals, priorities, and beliefs about who we should be in the world (Kram, Wasserman, & Yip, 2012). Because identities often overlap, it is not uncommon for healthcare professionals to experience conflict between them and to feel confused about how to manage these conflicts (Osteen, 2011). Interestingly, there are relatively few studies that focus on the development of identities or conflict between identities in medical professions, an area where due to high professional demands this might be especially relevant.

The field of healthcare has traditionally embraced a clear role division between patient and provider (Fox et al., 2011; McKevitt & Morgan, 1997). This can create difficulty for healthcare providers when personal and professional identities overlap or when they experience conflict between different identities. Providers who share with colleagues something they know from personal experience may be perceived as unprofessional (Browning et al., 2011), reflecting the underlying, socially-constructed value that providers should have knowledge not from personal experience on the receiving end of healthcare, but from a separate place of expertise. While there have

been clear historical values around clear and separate personal and professional identities, there are efforts being made to help providers integrate who they are personally into their practice (Browning et al., 2011; Osteen, 2011).

One example of this may be seen in a team of seven, multidisciplinary providers in Boston who, over a seven year period, conducted 3-6 hour workshops in which participants join life enactments in how to talk with patients and their family members followed by guided discussion of individual process-oriented reflections (Browning et al., 2011, p. 152). They write:

A key discovery for clinicians in our workshops is that the lion's share of expertise needed to be competent in these conversations derives not from expert-driven knowledge injected from the outside, but rather from already-existing knowledge linked to their personal experiences, with patients and families, and their collaborative, interprofessional experiences as members of healthcare teams.

While there are a number of different theoretical frameworks that can be used to understand how healthcare providers work with patients and families, systems theory adds a new lens to a traditionally individualistic medical model. This framework allows me to approach this study with an understanding that the impact of illness is relational and affects families as well as individuals. This relational approach to healthcare has been shown to be beneficial (Marshall, Bell, & Moules, 2010; Wright & Bell, 2009), but is still not commonly practiced (Borins, Holzapfel, Tudiver, & Bader, 2007). Adding to this, a narrative theory framework addresses the social construction of personal and professional identities that traditionally keep providers from relating too closely with their patients (Browning et al., 2011; Fox et al., 2011). It is clear that inclusion of family members in

care is important, and that providers are also impacted by their own experiences with

illness (McDaniel, Hepworth, & Doherty, 2003). Through this study, I will use systems

theory and a narrative framework to understand how these concepts are related.

CHAPTER THREE

REVIEW OF THE LITERATURE

With the development of George Engel's biopsychosocial model (1977), healthcare providers began to look at the emotional and relational experiences of patients suffering with illness. Yet across disciplines, training does not include self-reflection on the provider's own experiences with illness and how these may impact care given to families (Erlingsson, 2009; McDaniel, Hepworth, & Doherty, 1992; McKevitt & Morgan, 1997). Because a focus on self-of-the-provider isn't often a strong part of curricula in individual or interdisciplinary education (McDaniel, Hepworth, & Doherty, 1992), students may find themselves fearing that connecting too closely with patients' experiences may make them "less professional" in some way (McKevitt & Morgan, 1997). The combination of lack of training and an environment which fosters an individual rather than relational focus is in direct opposition to the body of research which tells us that a systemic, family-focused perspective in healthcare is beneficial (Marriott, Donaldson, Tarrier, & Burns, 2000; Hopkinson, Brown, Okamoto, & Addington-Hall, 2012; Martire, 2005).

Illness Narratives in Training and Practice

There are several themes in research regarding illness narratives across the disciplines of medicine, nursing, and family therapy. First, we know that illness narratives are important: providers' own experiences impact the formation of professional and personal identity (Browning et al., 2011), and affect how patients are viewed and care is delivered (McDaniel, Hepworth, & Doherty, 2003). Second, in most cases,

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providers are trained in ways that create separation between themselves and their patients (Fox et al., 2011; Klitzman, 2008), resulting in caregivers who tend to view healthcare and illness through an individual, rather than relational, lens. This may result in inadequate care for patients and their families (Borins, Holzapfel, Tudiver, & Bader, 2007). Missing in the literature is the connection between these. Thus this review will focus on what we need to know about what creates the link between providers' own experiences and their ability to see patients and family members in a relational way that results in better family-focused care.

In the following chapter, I will review two primary areas of the literature: illness narratives in healthcare training and practice, and inclusion of patients' families in healthcare. I will begin with a review of the literature on illness narratives in training and practice across three disciplines – medicine, nursing, and medical family therapy – and will outline how cultures in healthcare promote an individualistic perspective of health and illness, impacting providers' personal and professional identities and the quality of care delivered to patients and their families. In addition, the review will highlight studies that demonstrate how a more systemic understanding of the impact of illness may be beneficial to both patients and providers. In the second part of this chapter, I will discuss the inclusion of patients' families in healthcare, why this is important, and how this has been shown to be helpful. The review will include outlines of several successful programs aimed at including family members in care. The chapter will conclude with a discussion of how further research is needed in understanding how providers' own experiences impact the development of a more relational approach, and therefore better care for patients and families.

Medical Students

The culture of medicine has traditionally promoted clear role division between patient and provider based on the belief that patients are ill and in need of treatment and providers are healthy and possess the skills to heal sickness (Fox et al., 2011). This mentality promotes an "invisible line" (Fox et al., 2011, p. 1255) between the two, and may cause physicians to feel that a great deal of their identity lies in their ability to identify and define illness in others (McKevitt & Morgan, 1997). The obstacles that they face in this process may include internal forms of denial ("the magic white coat"), the need to self-diagnose and treat for fear of judgment from others, seeing themselves as "screw-ups" or dysfunctional in some way, and being ostracized by other providers (Klitzman, 2008).

Because of the value placed around this definition of professionalism, medical practitioners tend not to seek help when they themselves experience illness (Baldwin, Dodd, & Wrate, 1997), believing that "illness doesn't belong to doctors" (McKevitt & Morgan, 1997). This can be a lonely experience and one that causes a significant amount of stress for both provider and patients; the emotional and relational difficulties of illness, including shame, guilt, and separation, are often unaddressed in this setting, leaving physicians to feel anxious and reactive to these same emotions in the families they see (Stein, 1998).

While the culture around the medical model remains strong, students in some programs are being trained in "narrative medicine," a way of practicing that does not consider providers as invulnerable to illness or to the impact of patients' illness narratives (Charon, 2006). Centers for active practice of narrative medicine include Columbia

University, with its Master's program in narrative medicine, and the narrative medicine program at Western University in Canada. This type of work requires that providers remain open to being impacted by their patients; a difficult task when one sees suffering for a living. Research on the effectiveness of narrative medicine is scarce, due in part to the field's emphasis on evidence-based, quantitative research. It is only recently that there has been a call for the inclusion of qualitative research that would extend more easily to narrative medicine research, although this has yet to truly happen (Misak, 2010).

Some medical programs are encouraging students to think about how their own experiences impact their relationships with patients through specific academic activities. Instructors at the University of Michigan Medical School designed a program called the Family Centered Experience (FCE) to support students in connecting better with patients and their families. This can be through a number of different activities, including partnering with an individual or family experiencing chronic illness and journaling about what that experience might be like for them, putting together poems, stories, or songs that detail students' own reactions to talking with these families, and discussing in small groups what might students have learned and want to take forward from these experiences (White, Perlman, Fantone, & Kumagai, 2010).

Researchers in the Schools of Medicine and Dentistry at the University of Alberta in Canada put together a Patient-Centered Course (PCC) for first-year students, using film and small-group debriefing conversations as a way of helping students to self-reflect on their own experiences, those of the patients and families depicted in the films, and the relationship between these two. These experiences are intended to provide students with a better understanding of how patients and their families are impacted by illness.

Students in their second year are asked to write about "The Patient's Story" as a way of further exploring the relational impact of illness, while third and fourth year medical students write "parallel charts" on families non-clinical experiences with illness (Brett-Maclean, Cave, Yiu, Kelner, & Ross, 2010).

For the small number of studies demonstrating how self-reflection of the provider is being integrated into program curricula, outcome data is limited. In both the Family-Centered Experience and the Patient-Centered Courses described above, effectiveness is measured by students' reports on the helpfulness of these projects in understanding what patients and their families may go through in their experience with the healthcare system. Further research is needed around specifically how these activities are helpful for providers in becoming aware of their own experiences with illness, if or how this changes their practice with patients and their families, and whether or not patients experience a difference in working with providers who take a more relational approach to illness.

Nursing Students

There is a small body of research on several specific programs where healthcare instructors are working to incorporate self-reflection and a better understanding of the systemic impact of illness into classes for nursing students. However, similarly to medical students, these programs are few and the outcome results of these studies are quite limited. Likely the most well-known of these programs is the Family Nursing Unit of Calgary, which, until its closing in 2007, was a frontrunner in the world of progressive, systemic nursing education. Their model of care was characterized by a systemic, relational approach that combined both nursing and family therapy theories, and students

trained there often took part in research studies on self-of-the-provider, including writing therapeutic letters to patients' families and practicing clinical skills in understanding patients' beliefs about illness.

One significant study to emerge from the Family Nursing Unit addresses the impact of a "reader's theater" intervention used by researchers with a husband and wife who recently lost their adolescent son.   The researchers anticipated that the process of co-writing about their therapeutic experience would be healing for the couple, but found that it was the experience of reading what they'd written to one another to be the most helpful. Most significant to this study, the researchers found themselves constantly reflecting on how their own personal beliefs about illness and healing interacted with those of the couple throughout this process. This finding suggests that providers' own beliefs about illness and healing impact how they view patients and their families and work with them (Levak, McLean, Wright, & Bell, 1998).

Researchers in the nursing school at the University of Kalmar in Sweden borrowed ideas for self-reflection and family nursing practices from the Family Nursing Unit in Calgary, asking nursing students in their primary care practicum to do live interviews with families about their experiences with illness and then write therapeutic letters to these families. Twenty-nine letters were written by students and the researchers analyzed these using qualitative content analysis and coding where letters were scored against a checklist developed by the researchers using key ideas from the Family Assessment Model of Calgary. The researchers found three groups of letters: letters which distanced providers from families, letters which simultaneously pulled and pushed away families from providers, and letters that were uplifting to families. In addition, the

researchers found that students often had a difficult time distancing themselves from the "expert" role that they'd been exposed to in previous classes and clinical work. Lastly, students often reflected on their *own* experiences in these letters, rather than those of the patient and family, further indicating that providers' beliefs about illness affect patients' care (Erlingsson, 2009).

A group of three nurse educators at the University of Toronto in Canada conducted a recent self-led study on their experiences in processing with one another the systemic changes illness had brought to their lives. Realizing that each of their personal encounters with illness had impacted them in significant ways, they believed that it was important for them to process as a small group the meaning they made of those experiences. Through personal journaling, sharing stories together, and using artwork and metaphors, these researchers found that this process of reflection allowed them to experience illness in a new way that was held between the sharer, the listener, and the illness. There was great comfort for them in knowing that some of the elements of their experiences were shared, and that they were not struggling alone (Schwind, 2003).

From these studies, we know that an increasing number of programs are attempting to include self-reflection of the provider into their training, that students may struggle with conflicting personal and professional identities (i.e., empathizing with patients' stories, and still taking the "expert" role), and that students are often unaware of how their own beliefs about illness impact the way they view patients. However, most of the research on this topic involves small sample groups of only one institution, and as many of them note in their limitations, analysis is subjective and implications often vague. Still missing is a clear understanding of how awareness of one's own beliefs

about illness leads to the development of a more relational approach to healthcare and the inclusion of patients' family members in care.

Medical Family Therapy Students

Given medical family therapy's focus on relationships, it might be assumed that students in this field have a better understanding of the systemic impact of illness than students in other disciplines. While self-of-the-provider may be included in training for therapists, there is little evidence of attention in academic training given to the connection between providers' own narratives and those of their clients (McDaniel, Hepworth, & Doherty, 1992). Although it is frequently cited in the illness narrative literature, the book *The Shared Experience of Illness: Stories of Patients, Families, and their Therapists*, is not especially recent. The body of research on this subject is dated, and very few studies describe specific methods for helping medical family therapists reflect on their own experiences with illness. As a result, students may not recognize how their own experiences impact the way that they work with patients in the medical setting. For example, therapists may be more attuned to the stories of patients that they connect with personally, or may unconsciously tune out the experiences of those who remind them negatively of something they have experienced in their own lives (McDaniel, Hepworth, & Doherty, 2003).

Although family therapy training involves a focus on systems theory, medical family therapy students find themselves working in the same environment as medical and nursing students: one that favors a clear professional division between provider and patient. They are not immune to the values in this system, which include being objective

and rational, and may find themselves working to keep a safe distance between their professional and personal lives (Weingarten, 2010). Given their training, they may find themselves too easily focusing on the mind without taking into account the body (McDaniel, Hepworth, & Doherty, 1992), and while looking at the emotional experience of loss, may forget that there is a very real physical process happening as well. This may result in therapists who continue to struggle alone with the impact of illness on their own lives, and at the same time leave out important parts of patients' experiences as well.

In the book *The Shared Experience of Illness* (2003), editors Susan McDaniel, Jeri Hepworth, and William Doherty explored the relationship between medical family therapists and their patients by asking the therapists to write about both the patient and provider sides of illness. In reading these narratives, the editors found that self-reflection on the part of the therapist can be one of the greatest tools s/he has: it may allow the therapist to connect more deeply to what the family is going through without self-imposing his or her own story (McDaniel, Hepworth, & Doherty, 2003). Through the stories shared by the medical family therapists and their patients, ten emotional themes emerged: denial versus acceptance, despair versus hope, secrecy versus sharing, guilt versus forgiveness, burden versus relief, isolation versus connection, passivity versus taking charge, fear versus courage, loss versus renewal, and senselessness versus meaning (McDaniel, Hepworth, & Doherty, 2003).

The medical family therapy literature closely matches that of medical students and nursing students in several ways. Training across disciplines leaves students working in the medical setting with the impression that providers should maintain a level of distance with patients. This may leave students feeling confused when their own beliefs

about illness impact the way they view and work with patients and their families. Because self-of-the-provider reflection is not generally included in training, many students are unaware of their own beliefs about illness, and therefore unaware of how these impact the care they give to patients and their families. The practice of self-reflection has been found to help close the gap between what students learn in theory and practice, and further research is needed in how students cross this bridge and develop a more relational understanding of illness which may result in a more systemic practice with families being included in care.

Inclusion of Family Members in Care

Why is Caring for Families Important?

For many years, it has been well documented that families impact health and that it is important for healthcare providers to know how to work with families (Doherty & Campbell, 1998; McDaniel, Hepworth, & Doherty, 1992). Family members carry a great deal of clout: they have the ability to influence and encourage patients and to help them improve and maintain self-care. Patients with a variety of medical conditions, including cancer (Hopkinson, Brown, Okamoto, & Addington-Hall, 2012), heart disease (Coyne & Fiske, 1992) Alzheimer's disease (Marriott, Donaldson, Tarrier, & Burns, 2000) and substance abuse (Mueser et al., 2009) experience better outcomes when family members are involved in care.

The author of a recent meta-analysis of twelve quantitative, randomized and controlled studies examined how patients with various chronic illnesses respond to the inclusion of family members in care. Five of the twelve studies showed that working

with the family was significantly more beneficial than working solely with the individual; only one study showed that working with the individual was more effective. In the latter, at least one partner had been diagnosed with rheumatoid arthritis and partners going to self-management sessions with them reported decreased sense of self-efficacy and increased levels of fatigue. Additional studies showed that satisfaction with inclusion of family members in care depends on other factors as well, including the gender of the patient (female patients described higher levels of benefit), type of therapeutic intervention used, and amount of time until follow-up assessment was conducted (Martire, 2005).

Including family members in care is beneficial for not just the patient, but for family members and healthcare providers as well. Family members whose voices are heard and opinions considered may experience increased feelings of validation and strengthened family relationships (Martire, 2005). Providers that incorporate families into treatment provide better care (Sawa, 1988) and may experience better collaboration with other healthcare disciplines. Joint activities between disciplines are helpful, not only for understanding how specific approaches can compliment one another, but in pushing providers to further develop skills in treating not just the physical but the emotional and relational aspects of patients' health as well (Harkness & Nofziger, 1998).

Attempts to Include Families in Care

George Engel is credited with introducing the biopsychosocial model into the world of medicine, causing healthcare providers to consider the impact of illness on patients' relationships for the first time (Engel, 1977). Building on Engel's model,

Gregory Bateson (1972) began to introduce concepts of systems thinking into medicine as he incorporated families into the care and treatment of patients struggling with schizophrenia. Several decades later, the field of medical family therapy has attempted to continue this work by addressing the emotional and relational aspects of illness through a systems theory lens (McDaniel, Hepworth, & Doherty, 1992).

Although researchers have a better understanding of why families are important to healthcare, it is unsettling that since the origin of the biopsychosocial model forty years ago, not much has changed to move us from this theoretical understanding to a more practical inclusion of family members. Education for most professions is still centered around the traditional biomedical model of training which does not adequately address the family or how to include them in care (Kiuttu, Larivaara, Vaisanen, Keinanen-Kiukaanniemi, & Oja, 1996). As a result, healthcare providers graduate without the skills needed to translate what continues to be shown as beneficial to patients, families, and providers into actual clinical work (Borins, Holzapfel, Tudiver, & Bader, 2007).

Family Systems Healthcare

In the fields of both nursing and medicine, advocates for family systems practice have attempted to incorporate this into their work. Lorraine Wright and Maureen Leahey (1990) coined the term "family systems nursing" in an attempt to make a purposeful shift towards highlighting interventions directed specifically at the family (Bell, 2009). Similarly, Donald Block (1983) developed the term "family systems medicine" in an attempt to bring together family therapy, systems theory, and the practice of medicine. Each of the sub-specialties of family systems medicine, family systems nursing, and

medical family therapy are extensions of Engels' biopsychosocial model and the introduction of systems thinking into healthcare (Steinglass, 2006), and a great deal of the literature on family healthcare is written by people practicing out of these specific units (Bell, 2009).

As much as this model has been pushed by advocates for family care, family-centered medicine has not taken off the way that people thought it would (Steinglass, 2006). This may be partly due to the way our current healthcare system is set up with its basis in free-market economic principles, and as a result, attempts to integrate these ideas into medical training are not working because of time and financial constraints (Steinglass, 2006). Because integration of these ideas works best if it is originally and comprehensively included in education, this presents a challenge to including family members in care. To do so would require us to "make a conceptual shift, even a paradigm shift to account for interaction and reciprocity between health/illness suffering and family functioning, the interaction between themselves and the families in their care, and also consider the larger systems within which families and healthcare providers exist" (Bell, 2009).

Successful Programs for Family Healthcare

Can family healthcare skills be taught? The answer is yes. Current centers specifically integrating systems theory for family care include the Calgary Family Therapy Centre, Denise Latourelle Family Nursing Unit in Montreal, Chicago Center for Family Health, Institute for the Family at University of Rochester, Family-Focused Nursing Unit in Sweden, Family Stress and Illness Program in Pennsylvania (Bell, 2009).

In addition to these programs, medical, nursing, and family therapy researchers have conducted a significant number of studies on ways that inclusion of families in care can be taught and what might be beneficial in facilitating this learning process.

Finland Study

In their study of family systems medical training, a group of physicians in Finland looked at differences between ten general practitioners in a family-systems based two-year program (one day, every other week) and a control group of another fourteen practitioners taking traditional training in general medicine (Kiuttu, Larivaara, Vaisanen, Keinanen-Kiukaanniemi, & Oja, 1996). Training included looking at the relationship between providers and patients, systems theory, and biopsychosocial care. Participants in the family-systems group had the opportunity to take part in constructing their own genograms, as well as participating in role-playing and live supervision.

Participants in this study (Kiuttu et al., 1996) wrote reports of their patients, and researchers categorized these into four groups that described the provider's orientation: symptom-focused, patient-focused, family-focused, or systems-focused, using markers of how the physician was conceptualizing the illness (separate from or part of the patient), how she or he attended to the patient's unique needs or life story, and how she or he took into account how the illness might impact the family system.

The researchers found that during the 1st year, the control group was at 90% symptom-focused or patient-level orientation with only 10% at family or systems level versus 81% and 19% for the participant group. Changes became even more pronounced during 2nd year, when nearly half of the participant group (51%) fell into the family or

systems-level thinking categories. Participants in this program also consulted

significantly more often with family members at the end of the test than at the beginning

(Kiuttu et al., 1996).

Ontario Study

Researchers in Ontario, Canada conducted a training in counseling skills over five

weeks throughout the course of a year for fifty-five family doctors. Similar to the study

conducted by Kiuttu et al. (1996), some of the interventions used with participants

included mentoring groups, genograms, and role-playing. Using a questionnaire called

the *Carkhuff Discrimination Skills Index* designed to measure participants' understanding

of the verbal and emotional messages given by patients and how well providers'

responses matched these needs, researchers measured participants before beginning the

study, at the end of their five weekends, and six months later. They found that at the end

of the training, all participants had significantly increased in their abilities to connect with

and communicate effectively with patients. Additionally, approximately 50% of

participants continued to demonstrate increase skills at a follow-up 6 months later

(Borins, Holzapfel, Tudiver, & Bader, 2007).

It is clear that across healthcare disciplines, illness narratives are important in that

they affect the formation of professional and personal identity (Browning et al., 2011),

and the ways that patients are viewed and care is delivered (McDaniel, Hepworth, &

Doherty, 2003). Most providers are trained in ways that create separation between

themselves and their patients (Fox et al., 2011; Klitzman, 2008), and therefore tend not to

connect closely with patients or believe that their own experiences with illness might

impact the quality of care they give. This individual, rather than relational, way of looking at illness may result in inadequate care for patients and their families (Borins et al., 2007). The proposed grounded theory study will address this by looking at the how providers' own experiences with illness connect with their ability to see patients in a relational way that results in better inclusion of family members in care.

CHAPTER FOUR

METHOD

Because there is a minimal amount of research on the impact of healthcare providers' illness narratives, grounded theory is an appropriate methodology as it allows us to "discover theory from the data (Glaser & Strauss, 1967)." This type of exploratory study works well for beginning research on areas in which there is little or no previous study (Daly, 2007) and is "hypothesis generating" rather than hypothesis testing (Daly, 2007). It is also particularly useful in studies such as this in which the focus is on process and meaning. The goal of grounded-theory methodology is to create a theoretical framework that "fits" with the experiences of the participants - in this case, medical, nursing, and medical family therapy students.

Development of Grounded Theory

The development of grounded theory as a research methodology began in the 1960's when Barney Glaser and Anselm Strauss found themselves questioning many of the assumptions surrounding the established form of study at the time: quantitative research. Their pivotal book, *The Discovery of Grounded Theory* (1967), changed how many researchers were thinking and working. This provided space for researchers to move from the deductive process of testing pre-determined theories on participants to the inductive process of developing theory from the research (Charmaz, 2006). Glaser and Strauss's ideas were met with some contention, especially within the medical field where positivist, quantitative research was highly valued (Charmaz, 2006). As they continued to develop their method, Glaser and Strauss eventually went in different directions:

Glaser maintained that theory could be discovered, while Strauss partnered professionally with Juliet Corbin and used verification of categories as their method (Charmaz, 2006).

Methodological Assumptions

At the time of grounded theory's origination in the 1960's, quantitative research was the gold standard; researchers generally believed that knowledge is formed when we see things in an unbiased way and when we can repeat tests that will have the same results over and over for different participants (Charmaz, 2006). From this standpoint, the researcher discovers things from his or her participants but he or she does not co-create this process in any way; the focus was on facts, and not intuition. Although the proposed study will not represent students from every healthcare discipline or those with more experience, I anticipate that the grounded theory themes created between researcher and participant will resonate with the experiences of many. In addition, a grounded theory approach to this study may provide information about the relationship between providers' experiences and those of their patients that is useful and widely applicable to collaboration across disciplines.

Criticisms and Debate

There are several criticisms of grounded theory that were and continue to be debated, both from between groups of grounded theorists, such as Glaser, Strauss, Corbin, and Charmaz, and from researchers of other methodologies. These include whether or not data is discovered (Glaser & Strauss, 1967; Corbin & Strauss, 1990) or co-created (Charmaz, 2006), and whether our biases are causing these "truths" to be

forced into pre-determined categories (Glaser, 1992) or if they are allowed to developed

naturally out of the data. Most notably within the last two decades, there has been a

significant push towards a more post-positivist approach (Charmaz, 2000) in which

researchers suggest that we cannot discover either theory or truth from the data; we can

only co-create it together with our participants (Charmaz, 2006).

For the purpose of this study, Charmaz's theoretical approach to grounded theory

is a good fit. Her approach is consistent with the themes of social constructionism and

narrative theories that state that our ideas about reality are held in our values and that

these values are often unspoken but still very present (Gergen, 2009; Madigan, 2010).

This way of looking at things leaves room for more than one perspective (similar to

narrative therapy's multistoried lives) and takes into account the influence of power and

asks whose voices may or may not be heard because of these taken-for-granted "truths."

This fits well with the idea that both healthcare providers and patients are more than

those labels, and that exploring the relationship between providers' experiences with

illness and those of their patients may lessen the power differential between them.

Method Overview

The proposed study will utilize grounded theory methods to explore students'

reflections on illness narratives and the experience of providing family-centered care in

the workplace. This study will be a subset of a larger research project led by Dr. Barbara

Couden-Hernandez, titled "Critical Life Narratives in Clinical Practice," which examined

medical students' beliefs about illness impact on their work. Dr. Barbara Couden-

Hernandez is listed as the Primary Investigator in the larger study, as well as this

proposed study. Currently, listed researchers on the proposed study include Dr. Barbara Couden-Hernandez (PI), Carmen Knudson-Martin, and Lindsey Lawson. Both studies have been approved by the Loma Linda University Institution Review Board and are in progress.

Data will be gathered from interviews and field notes and I will analyze this data using grounded theory coding methods for student groups (Charmaz, 2006) and NVivo software. This will allow me to develop theory regarding the ways in which formative life experiences and education come together for young healthcare workers in training. Participants will be interviewed at sites determined in collaboration with participants, likely at their homes or workplaces, or through Skype. In doing this research, the aim is to better understand how healthcare providers' awareness of their own personal illness narratives impact the way that they approach inclusion of patients' family members in care.

At the time of this proposal, data has been collected from two of the three sample groups: medical and nursing students. Nineteen interviews have been collected from the medical student sample group (as a part of the "Critical Life Narratives in Clinical Practice" study), and ten interviews have been collected from the nursing student sample group. Dr. Barbara Couden-Hernandez will use interviews only from the medical student group, while this study will use samples of ten interviews from each of the three groups. Outlined below are detailed descriptions of the ways students were recruited and interviews collected for the already-existing interviews. Interviews are being transcribed as they are collected and analysis, including field notes and memos, is taking place concurrently.

Length and Scope of Study

The "Critical Life Narratives in Clinical Practice" study began in January of 2011. All interviews for the medical students in this larger study have been collected. As a part of this larger study, the current proposed study also began in January of 2011 and will be conducted until December of 2013. A proposed completion for the dissertation is December 2013, with the publishable paper manuscript submitted to *Families, Systems, and Health* or *Qualitative Health Research* between June 2013 and December 2013.

Sample Selection

The proposed study has followed a stratified sampling plan with participants including nursing students (Loma Linda University), medical students (Loma Linda University), and medical family therapy students (Seattle Pacific University, East Carolina University). Inclusion criteria for both the larger and currently proposed study include (1) self selection by participant, (2) ability to speak English, (3) accepted into an undergraduate nursing program, medical school, or graduate medical family therapy program. To date, interviews for the proposed study have been conducted with medical and nursing students sample groups, but not the final sample group of medical family therapists.

Nursing Students

Ten nursing students from Loma Linda University participated in this study through interviews collected between Fall of 2010 and Spring of 2012. Administrative faculty at Loma Linda University School of Nursing sent students who had been accepted

into the undergraduate nursing program an invitation to participate in this study along with their standard program materials sent to new students (Appendix D). The informed consent (Appendix F) was included in the mailing in a self-addressed, stamped envelope that was returned by students willing to participate in the study. Either Dr. Couden-Hernandez or I contacted participants to arrange an interview at a mutually agreed upon site (Appendix H). At that time, participants completed the demographic questionnaire (Appendix I) in order to obtain basic information about their personal and professional history.

The informed consent (Appendix F) was reviewed by the interviewer with participants before beginning the interviews. Students were informed that their decision whether or not to participate in this study would not be known by anyone in their department, and that it was being conducted by individuals not affiliated with the school of nursing. The existing interviews have been audiorecorded and are currently being transcribed. In the unlikely event that the participant was to become distressed about the content of their conversation, a list of three counseling resources was provided in the informed consent (see Appendix F). Field notes, consisting of impressions of the participant and their comments were recorded by the interviewer immediately after leaving the interview site. Nursing students from LLU were given a $10 gift card to either Starbucks or iTunes for their participation.

Medical Students

Ten medical students from Loma Linda University also participated in interviews conducted in Spring and Summer of 2012. Academic Vice President for Student Affairs

in the School of Medicine was contacted with the request to invite Loma Linda University medical students to participate in this study (Appendix D). Emails were sent to all medical students containing contact information for LLU investigators, who were either emailed or called by potential participants (Appendix H). Either Dr. Couden-Hernandez or I contacted participants to arrange an interview at a mutually agreed upon site. At that time, the participant completed the demographic questionnaire (Appendix I), and the informed consent (Appendix F) was reviewed by the research team member with the participant before beginning the interview.

Just as with the nursing sample group, medical students were informed that their decision whether or not to participate in this study would not be known by anyone in their department, and that it was being conducted by individuals not affiliated with the school of medicine. The interviews were then audiorecorded and are currently being transcribed. In the unlikely event that participants were to become distressed about the content of their conversation or indicate that they want to speak with a counselor, a list of three counseling resources was provided in the informed consent (see Appendix F). Field notes, consisting of impressions of the participant and their comments were recorded by the interviewer immediately after leaving the interview site. Because recruitment for the nursing sample group was more difficult than anticipated, it was decided that medical students would be offered a increased gift card of $25 to either Chipotle or Starbucks for their participation.

Medical Family Therapy Students

Interviews with Medical family therapy students have not yet been done. Chairs

of the Departments of Marriage and Family Therapy at Seattle Pacific University (SPU), Claudia Grauf-Graunds, and East Carolina University (ECU), Angela Lamson, will be contacted with the request to invite medical family therapy students to participate in this study (Appendix E). MFT faculty at these schools will send a mass email to their current medical family therapy students inviting them to participate in the study. Announcements may also be made in class by reading the email message in the classroom. The email message will contain contact information for LLU investigators, who will be either emailed or called by potential participants (Appendix H).

The investigators will send an informed consent document (Appendix G) to prospective participants in a self-addressed, stamped envelope. Once this is received, I will contact the volunteers to schedule Skype interviews that will be audio-recorded. The informed consent issues will be reviewed before the interview begins and an opportunity will be provided for participants' questions to be answered. Field notes, consisting of impressions of the participant and their comments, will be recorded by the interviewer immediately after conducting the interview. Medical family therapy students will be given a $25 gift card to either Chipotle or Starbucks. Should participants experience emotional distress talking about difficult life events, they will be given a referral list to three local therapists included in the Informed Consent.

Interviews with medical family therapy students will add to the bank of already-existing interviews by medical and nursing students. I plan to collect interviews with a minimum of 10 and maximum of 15 participants in each population category (30 - 45 participants in total), or until we have attained saturation. We will know when we have reached this point when new data no longer leads to changing grounded theory, and when

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no new categories are being developed (Charmaz, 2006). As the interviews are being collected, they will be transcribed verbatim by members of the research team and all identifiers will be removed. The audiotapes will be destroyed. The research team will use grounded theory coding methods as noted above, and will include field notes in the data analysis. NVivo software will be used to develop themes and sub-themes from the data to address the four research questions stated above.

Transcription and Data Storage

Care will be taken to maintain participant confidentiality throughout the study. Demographic data, contact information, interview transcriptions, and field notes will be locked in an office file cabinet of the primary researcher. Once interviews have been collected and transcribed, the audiotapes containing these interviews will be destroyed. In the transcription process, names and other identifying information will be removed and a code will be given to the transcript.. For example, the first medical family therapy student may be coded, "MFT1." Only I and the dissertation committee will have access to the interview tapes and confidential identifying information of the study participants.

Before beginning the interviews, I will address issues and limits of confidentiality through the informed consent (Appendices F and G). In the unlikely event that a participant reveals unethical healthcare practices which are endangering patients' lives, I will take steps to maintain patients' safety that may include discussion with department faculty or hospital employers. Participants will be made aware of this small possibility before each interview begins and will be asked whether or not they would like to continue on with the study. .

Data Creation and Analysis

In keeping with grounded theory methodology (Glaser & Strauss, 1967), creation of data and analysis will occur simultaneously. This is continuous throughout the research process as I collect interviews, transcribes and codes them, and writes memos and notes concurrently and then uses emerging hypotheses back to inform future interviews. I will be utilizing Kathy Charmaz's postpositivist approach, through which she suggests that truth is generated between researchers and participants, rather than existing and being found by the researcher (Charmaz, 2006). This fits well with the social constructionist and narrative theories perspectives that guide this study and reinforce a more relational approach to research (Madigan, 2010).

When interview questions for this study were originally developed for the larger study "Critical Life Narratives in Clinical Practice" two years ago, we wanted to dig deeply into three broad areas: the experiences students have with illness, the culture of support or shame around these experiences in their respective disciplines, and the impact of these experiences on care for patients and families. From these broad areas, we ask probe questions to help us understand the meaning and process for students behind these experiences. Sample questions from the interview guide include, "As healthcare workers, we often find ourselves connecting with certain patients and relating to their lives. Has this ever happened to you? Can you tell us about that experience?" and "In what ways has [your own experience with illness] impacted you personally and professionally? How do these ideas influence the way you approach people with illness?"

Initial Line-by-Line Coding

In accordance with grounded theory methodology, analysis of the interviews happens throughout the process of research (Charmaz, 2006). Therefore, rather that beginning this study with pre-set categories or specific hypotheses to prove, I will use line-by-line coding (Corbin & Strauss, 2008) to look for themes that relate to a relational approach to illness, including ways that students are aware of the impact of their own experiences with illness, the systemic ways that they see illness impacting people, and their interactions with patients' family members. Initial line-by-line coding will include my interpretations of the overall message of that line. For example, if a student states, "My family believes that if people don't take care of themselves, it's their own fault if they wind up sick," I might code, "Family values preventative self-care, autonomy."

Axial Coding

As I move through coding individual lines of transcripts, I will begin to look for categories, or themes, in the data. This begins to bring the data back from individual line-by-line codes into a whole that begins to help me understand how this process is happening. I will use a constant comparison method (Corbin & Strauss, 2008) to determine whether or not there are variations in these themes and how these might relate to variations in other categories. For example, if a participant states, "It makes me feel really uncomfortable to work with families… I just haven't had that much experience with it, but I hope maybe that will change," I might code: "desires skills to work effectively with patients' families."

Throughout this process I will continue to keep analytic memos to note my

reflections as interviews are conducted and coding evolves. Examples of analytic memos during interview collection might be, "Student seems to experience heightened emotion as she talks about the frustration of working with patients who do not practice preventative care – she talks more rapidly and moves her hands in her lap," or "I wonder what it would be like for students to feel supported in working more with patients families? Would this feel too vulnerable for them? What would be helpful in this process?"

Theoretical Coding

As I move from analyzing line-by-line and axial themes, I will look for re-emerging themes around how providers' experiences impact their ability to work with families in a relational way. In other words, I will move from looking at the nuances of interviews in line-by-line coding, to developing categories in axial coding, to beginning to look at relationships between themes and how they fit together in theoretical coding. For example, I might code "family values preventative self-care, autonomy" and "frustration in working with patients' families" as "individual illness perspective," or "belief in impact of support system" and "desire to incorporate families in care" as "relational illness perspective." The practice of constant comparison (Corbin & Strauss, 2008) between codes and broader categories will continue throughout the research process, and I will meet regularly with the PI and dissertation chair to challenge and elaborate coding and the evolving theoretical model.

Self of the Researcher

Many grounded theory researchers choose to share something about themselves that helps the reader to understand where they are coming from and how their interest developed in this specific area (Charmaz, 2006). This extends the relational process from the researcher and participants to include the readers as well. This will be very important to me in my work around illness narratives; not only in thinking about what will be most helpful to share in a small paragraph of a publishable paper, but also in my own process of continuously sorting through how my own experiences are impacting the way in which I am viewing the study. The selection of this research topic was related to an important event in my life which changed me both personally and in the ways that I work with families professionally.

Five years ago, my mother and brother were struck by a drunk driver, causing my mother to be in the hospital for several months with a badly injured leg. The accident happened only a few blocks from my parents' home, and when I heard ambulances going by, I walked down the road to see what was happening. By the time I got to the accident site, the top had been cut off of the car and my mom and brother had been taken to the hospital. I remember feeling this deep, deep panic as I saw the mangled car, barely recognizable but for the luggage peeking out of the back, without my family inside. I had no idea in that moment if they were alive or dead, but assumed that there was no way anyone could have survived a wreck like that. I remember spending that afternoon in the hospital waiting room, by myself, until my dad arrived. Once he had been there for several hours and knew that they were stable, he had to leave to drive back to work several hours away and I spent the night alone in our house.

This event was life-changing in a number of ways and raised several questions for me that are addressed in this study. It was at this point that I became curious about if or how providers' own experiences with illness impacted the way they viewed and worked with patients. I was suddenly more aware of families, rather than individual patients, as recipients of care, and wondered if families were as impacted by illness as the patient and whether or not their needs were ever addressed. These questions were closely connected to a new awareness of the relational impact of medical complications: the more reflective I was on what was helpful for us as a family during this time, the more I wanted to do those same things for other families as well. I intend to continue to be accountable to these personal processes through transparency of my experience as a patient, nurse, and medical family therapist in my writing and presentation of this study.

Validity

Rather than describe the quality of work in terms of validity, grounded theory researchers use words like "trustworthiness" and "credibility" (Daly, 2007; Glaser & Strauss, 1967). In this study, the research process will be co-created between participants, the researcher, and readers (Glaser & Strauss, 1967). The researcher is not the expert in the sense of de-coding or drawing professional conclusions about the data. Instead, I will continue to check back with participants throughout the interview to make sure that what is being reported is being understood, and write in a way that includes detailed descriptions from participants (Glaser & Strauss, 1967). This will mean including a good number of quotes so that readers have the opportunity to fully see the research process and come to conclusions about the participants' experiences. I will stay

true to the full and complete process of grounded theory research methodology and will follow and clearly describe a defined analytic process (Glaser & Strauss, 1967).

In the proposed study, it will be important that results are described and presented in a way that resonates with the experience of the readers (Corbin & Strauss, 2008). Developing categories that fit well with others' experiences will require that I maintain flexibility in the process of constant comparison (Glaser & Strauss, 1967) and to continue to develop these categories throughout the entire research process. These categories will not apply to every unique situation; however, in the proposed study, I will strive to develop themes applicable to a wide span of healthcare providers (Glaser & Strauss, 1967). The results of these categories will be written about in a way that is easily understandable by not only other professionals of different disciplines, but by those not working in healthcare or academia as well (Glaser & Strauss, 1967).

One of the primary goals of grounded theory work is that it will motivate others towards action (Corbin & Strauss, 2008). In this case, I hope that it will inspire increased collaboration between disciplines and encourage medical family therapists to see out opportunities to help providers integrate families into care. In addition to producing change in the readers, it is expected that the process of grounded theory research will impact the researcher as well (Glaser & Strauss, 1967), something that I will be accountable towards in memos and notes throughout the process. Lastly, in an effort to meet the researcher transparency that is often a part of grounded theory research, I will briefly describe how personal and professional interests guide her interest and work in this area.

Limitations

There are several potential limitations to this study, one of which is that there may be significantly higher numbers of women than men participating, especially within the nursing student group and potentially from the medical family therapy group as well (interviews have not yet been done with this sample). This is an accurate reflection of programs which, because of social discourses around gender and power, generally attract few men. In addition, participants from both the nursing and medical student sample groups are located in Southern California, an area of the country with a unique culture which may be dissimilar to other parts of the United States. Because of the religious affiliations of the institutions from which students are being invited to participate, a high number of volunteers may be religious or spiritual. In addition, due to systemic privilege which allows Whites easier access to education, fewer students of color may be represented. Lastly, although nurses, physicians, and medical family therapists make up a significant sample of workers in healthcare, we cannot include participants from every discipline. Those in such fields as physical and occupational therapy, nutrition, pharmacy, and social work may find similarities or differences in their own narratives and how these impact their work.

CHAPTER FIVE

IMPLICATIONS

Although previous researchers have found that clinicians' beliefs about healthcare impact the way they work with patients and families (Griffith & Griffith, 1994; McDaniel, Hepworth & Doherty, 2003), results of these studies continue to be ignored across disciplines in training and clinical collaboration. Therefore, the primary goal of this study is understanding the link between providers' own illness narratives and the ways in which they understand illness (through an individual versus relational lens) and include patients' family members in care. This study has the potential to expand the existing knowledge base on the impact of self-of-the-provider on care given to patients and families, and may be particularly helpful for healthcare instructors and practitioners in training. In the following, I will outline several ways that results of this study may contribute to healthcare providers and teachers, including improved interdisciplinary training and collaboration and better patient outcomes. Lastly, results from this study may pave the way for future research on how self-reflection can be better integrated into healthcare teaching.

Improved Interdisciplinary Training and Collaboration

Interdisciplinary work is essential to what medical family therapists do: Linville, Hertlein, and Prouty Lyness (2007) define medical family therapy as "an approach to healthcare from a biopsychosocial-spiritual perspective, informed by systems theory, spanning across a variety of clinical settings where the patient's interpersonal relationships are believed to play a key role and collaboration exists between the family

therapist and other healthcare practitioners." McDaniel and Campbell (1997) reiterate the relationship between effective collaboration and improved patient care when they state that: "it is possible to provide decent patient care when professionals just *tolerate* each other. With uncomplicated patients, this may work okay. *Cooperation* implies actually adapting to each other's care, while *collaboration* involves shared inquiry" (p. 357). One of the main outcomes of the proposed study is to better understand how caregivers from other disciplines think and work, which may result in improved collaboration in the medical setting.

Sharing a Common Language

In order to collaborate effectively, medical family therapists and other healthcare professionals need to speak a common language (Harkness & Nofziger, 1998). Medical interactions are often characterized by short, punctuated briefings of patients with only the necessary information included (Ruddy, Borresen, & Gunn, 2008), and differences This may seem foreign to therapists who, in their own interactions, are usually thinking and talking systemically. These differences between action and process-oriented ways of understanding can be a challenge to collaboration, and both medical and behavioral health professionals need to take steps to find ways around this.

For medical residents and attendings, this may mean observing therapists as they work (McDaniel & Campbell, 1997), talking with MedFTs about contextual issues in patients' lives, and being open to processing their own internal reactions to their relationships with patients (Rolland & Walsh, 2005). For medical family therapists, finding a common language may mean exploring expectations of medical professionals

and finding ways to present important systemic information that might otherwise be overlooked in a way that is concise (Ruddy, Borresen, & Gunn, 2008). The process of listening to providers' illness narratives and exploring with them how these impact their work may result in improved communication between medical, nursing, and family therapy providers.

Interdisciplinary Training

Interdisciplinary training is essential to collaboration: different disciplines must learn *about* one another, and *with* one another (McDaniel & Campbell, 1997). Most healthcare professionals are attempting to learn how to collaborate once they are out in the field, instead, providers need to be educated about what this looks like throughout our training. Medical family therapists should have early exposure to classes with medical residents and be working alongside them in primary care settings, and residents should be observing therapists at work with patients (McDaniel & Campbell, 1997). While several of these activities are currently being practiced at the Loma Linda University Medical Center, there is further need for understanding about the differences in self-of-the-provider training between disciplines and how this impacts inclusion of families in care.

Treating Providers as Customers

As family therapists move into new medical settings, research shows that it is important that medical family therapists view just patients, but other healthcare providers as potential customers (Seaburn, Lorenz, Gunn, Gawinski, & Mauksch, 2003). This serves two purposes: it helps them to gain the trust of other professionals who will refer

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patients, and it provides a foundation for them to support other providers in their roles as well. This may include being proactive in discussing what collaboration means and how communication will happen (Seaburn et al., 2003), creating a system of intake and post-referral letters to be sent to providers (Ruddy, Borresen, & Gunn, 2008), and maintaining an "open-door" policy for frequent communication (Reitz, Fifield, & Whistler, 2011). Along with developing connections for the benefit of better patient care, this can also help in supporting other providers in their own work. Part of family therapists' role in collaboration then may be to support providers in eliciting their own illness narratives.

Improved Patient Outcomes

Attending to providers' illness narratives will have an impact not only on the lives of healthcare professionals, but on the way that services are delivered to patients. Research shows that collaborative care is cost-effective (Katon et al., 2006), and providers who collaborate openly have patients with significantly higher levels of satisfaction with their medical care (Deen, Fortney, & Pyne, 2011). Patients receiving collaborative care also demonstrate higher levels of physical improvement, including better management of blood sugars for patients struggling with diabetes (Arevian, 2005), greater long-term depression outcomes (Lin et al., 1999), and improved pain management (Dobscha et al., 2009). In addition, this type of whole-person care has been shown to be especially helpful for marginalized groups, such as ethnic minorities, immigrants, and those living in low socio-economic status (Kaltman, Alter, & Carol, 2011; Robinson & Reiter, 2007).

Conclusion

While there are obviously specific programs devoted to family systems medicine, textbooks written to give students exposure to these ideas in one or two classes, and researchers publishing on the importance of including family members in care, what is clearly emphasized in the literature is that these ideas are not often translated to practice (Wright & Leahey, 2009). Attention to the impact of illness on families seems to be seen as more of a professional specialty, rather than an essential foundation to care. Due to insufficient time, resources, and training, "family centered care requires beliefs and skills that traditional healthcare practitioners are often reluctant to embrace (Horwitz, Horwitz, Orsini, Antoine, & Hill, 1998)."

For example, Berman (1991) published a study in which nurses working in a children's hospital were interviewed about their thoughts on a family-centered model for care. Participants strongly agreed with the principle of including family members in theory, but in practice, did not follow through with this. As evidenced by this and other studies, there is a clear gap between theory and practice when it comes to healthcare providers including patients' family members in care. Bridging this gap depends on two things: changing the training to include family members, and providing a work environment that supports this (Horwitz, Horwitz, Orsini, Antoine, & Hill, 1998). In order to accomplish this, more information is needed on how providers develop a more systemic, relational approach to healthcare and illness. A first step in this may be the proposed study: understanding how healthcare providers' awareness of their own personal illness narratives impacts on the way that they approach inclusion of patients' family members in care.

CHAPTER SIX

PUBLISHABLE PAPER

Student Healthcare Providers' Illness Narratives:

Impact on Family-Focused Care

Illness narratives, or the way that people organize around the experience of illness, give insight into how people make meaning of their lives (Kleinman, 1989; Werner, Isaksen, & Malterud, 2004; Marshall, Bell, & Moules, 2010; Wright & Bell, 2009). Sharing these illness narratives with others is useful because it creates connection between our own experiences and others' (Schwind, 2003) and builds hope by confirming to both listener and speaker that the narrator will continue to cope with illness and tell his or her story (Monks, 2000). This experience of sharing is a recursive one that engages both parties in the process of thoughtful, healing reflection (Schwind, 2003). Illness narratives have been studied and documented in a variety of settings and with multiple populations (Charon, 2006; McDaniel, Hepworth, & Doherty, 2003; Wright & Bell, 2009); however, the impact of these narratives on the development of professional identities and providers' work in family-centered care has received little scholarly attention.

For this study, we use systems theory as an overarching framework and are additionally informed by social constructionism and narrative theories to help explain how providers' illness narratives impact their work with patients and families. A systems theory perspective of healthcare may be defined as the process of, "forging collaborative relationships between families and communities and community organizations that serve families (Doherty & McDaniel, 2010, p. 6)." From social constructionist and narrative

perspectives, we see the value of a systemic, family-focused view of healthcare.

Literature Review

Developing a Systemic Illness Perspective

We know that experiences of illness are felt by not just by individuals, but by family and friends as well (Marshall, Bell, & Moules, 2010; Martire, 2005). This challenges a culture of separateness in illness, and instead suggests that "relational suffering" (Marshall, Bell, & Moules, 2010) impacts not just the individual but larger systems as well, including family members, the community, and healthcare providers. However, professional training programs still struggle with helping students and providers to reflect on how their own experiences impact the care given to patients and families. For example, clinical practice values still include the ability to remain "objective", or to not be overly influenced by patients' experiences of illness, and to maintain a safe distance between one's professional and personal life (Weingarten, 2010).

While there have been clear historical values around defined and separate personal and professional identities, significant efforts are being made to help providers integrate who they are personally into their practice (Browning et al., 2011; Osteen, 2011). In the book *The Shared Experience of Illness* (2003), editors Susan McDaniel, Jeri Hepworth, and William Doherty explored the relationship between medical family therapists and their patients by asking the therapists to write about both the patient and provider sides of illness. In reading these narratives, the editors found that self-reflection on the part of the therapist can be one of the greatest tools s/he has: it may allow the

therapist to connect more deeply to what the family is going through without self-imposing his or her own story (McDaniel, Hepworth, & Doherty, 2003).

In all three of the healthcare disciplines included in this study, there are examples of educators working to promote a more systemic perspective of illness. Donald Block (1983) originated the term "family systems medicine" in an attempt to bring together family therapy, systems theory, and the practice of medicine. Similarly, Lorraine Wright and Maureen Leahey (1990) coined the term "family systems nursing" in an attempt to make a purposeful shift towards highlighting interventions directed specifically at the family (Bell, 2009). Programs such as the Calgary Family Therapy Centre, Denise Latourelle Family Nursing Unit in Montreal, Chicago Center for Family Health, Institute for the Family at University of Rochester, Family-Focused Nursing Unit in Sweden, Family Stress and Illness Program in Pennsylvania (Bell, 2009), and schools of medical family therapy such as Loma Linda University and East Carolina University all specifically teach family-focused care to students.

While we are learning more about the value of provider self-reflection, we still know little about how healthcare providers' own experiences impact their interactions with patients and whether or not they involve family members in care. The grounded theory in this study will show how the process of training students, providing them with support and mentorship, and asking them to reflect on their illness narratives helps them to confront this issue in different ways.

Method

To explain how healthcare providers' illness narratives impact their interactions

with patients and families, we used Charmaz's constructivist approach (2006) to grounded theory methodology. We begin with the assumption that helping providers across disciplines to attend to their own experiences with illness may have an impact not only on the lives of healthcare professionals, but on the way that services are delivered to patients. We anticipate that this study will expand the existing knowledge base around the impact of self-of-the-provider on care given to patients and families, and may be particularly helpful for medical family therapists, healthcare instructors, and practitioners in training.

Self of Researcher

I, Lindsey, worked as a nurse before shifting into a career in couple and family therapy. During this time, a close family member was hospitalized for a number of months with repeat surgeries after being hit by an intoxicated driver. The experience of being a family member on the receiving end of healthcare, rather than the giving end, was new and challenging. I found it frustrating that my family member's caregivers did not often address me or direct any information to me, even though I was constantly present in the room. This significantly changed the way I thought about the importance of family members in healthcare, and I began to make a conscious effort in my nursing work to call on families as a support and resource for patients, rather than a hindrance.

Grounded Theory Methodology

Because there is a minimal amount of research on the impact of healthcare providers' illness narratives, grounded theory is an appropriate methodology as it allows

us to "discover theory from data" (Glaser & Strauss, 1967, p. 1). This type of exploratory study works well for beginning research in areas on which there is little or no previous study (Daly, 2007) and is hypothesis generating rather than hypothesis testing (Daly, 2007, p. 3). The goal of grounded-theory methodology is to create a theoretical framework that "fits" with the experiences of the participants - in this case, medical, nursing, and medical family therapy students. We utilized Charmaz's constructivist approach (2006) to grounded theory, which emphasizes that analysis is not separate from the researcher, and theory is developed through our active engagement with participants in the data-creation process.

Participants

Students from two schools, Loma Linda University and East Carolina University, were asked to take part in this study. All twenty of the medical and nursing students were enrolled at Loma Linda University, while five of the medical family therapy students were from Loma Linda University and five from East Carolina University. Chairs of discipline-specific departments were contacted and asked to invite students to participate through a mass email describing the proposed study. Interviews were conducted in person (25) and over the phone or Skype (5). Participants ranged in age from nineteen to thirty-eight, with their median age being twenty-five. Twenty-seven participants were women, and three were men. Participants self-reported their ethnicities as Euro-American (21), Indian (1), Korean-American (1), Hispanic (2), and Asian (2). Three participants chose not to disclose this information. The majority of participants were single (16), with the remaining being married/partnered (14). Most did not have children

(28), and a high percentage of reported having meaningful religious or spiritual connections (24).

Data Creation and Analysis

In keeping with grounded theory methodology, creation of data and analysis occurred simultaneously. This was continuous throughout the research process as we collected interviews, transcribed and coded them, wrote analytic memos and notes concurrently, and then used emerging hypotheses to inform future interviews. As we developed an initial plan for this study, we wanted to dig deeply into three areas: the experiences students have with illness, the culture of support around these experiences in their respective disciplines, and the impact of these experiences on care given to patients and families. Sample questions from the interview guide included, "As healthcare providers, we often find ourselves connecting with certain patients and relating to their lives. Has this ever happened to you? Can you tell us about that experience?" and "In what ways have [your own experiences with illness] impacted you personally and professionally? How do these ideas influence the way you approach people with illness?"

Initial Line-by-Line Coding

To begin, the first author and a research assistant used line-by-line coding (Charmaz, 2006) to look for themes that related to a relational approach to illness, including ways that students are aware of the impact of their own experiences with illness, the systemic ways that they see illness impacting people, and their interactions

with patients' family members. Initial line-by-line coding included our interpretations of the overall message of that line. For example, when a student stated, "My family believes that if people don't take care of themselves, it's their own fault if they wind up sick," we coded, "Draws on individualistic family values."

Focused Coding

As we moved through coding individual lines of transcripts, we began to look for more focused themes within each of the three sample groups (Charmaz, 2006). Pulling codes that stood out to us from across the three groups, we compiled twenty-six pages of grouped codes that we clustered together under sub-headings. We used a constant comparison method (Charmaz, 2006) to determine whether or not there were variations in themes between and across different sample groups, and how these variations might relate to one another. For example, our focused coding for the medical student group included the subheading "definition of professionalism" with codes underneath this including, "importance of personal privacy in medical culture," and "providers with personal illness not seen as professional" with quotes from participants highlighting these codes.

Analytic Memos

Throughout all stages of coding, we also kept analytic memos to note our reflections as interviews were conducted and categories evolved (Charmaz, 2006). During focused coding, we found this to be especially important as we began to see "definition of professionalism" emerging as a core process. We noticed that while we

were clearly seeing the tension between medical and nursing students' definitions of professionalism and the connections they wanted to make with patients, this didn't seem as evident with the medical family therapy group. Part of our analytic memo on this included,

> What stands out most to me is the tension between being seen as a professional and connecting 'too closely' with patients and families. This seems to be different than the medical family therapy group. Is there is a different definition of professionalism in the MedFT culture of training and work?

Theoretical Coding

As we moved from clustering codes under sub-headings and comparing and contrasting categories across different sample groups (Charmaz, 2006), we saw four common themes, all connected to a core construct around the tension between the development of professional identity and students wanting to connect emotionally with patients and families. These themes included (1) students facing discrepancies between their ideals about what it would mean to be a healthcare provider and their actual lived experiences, (2) coping with the challenges of healthcare culture (including power and hierarchy), and experiencing pressure to conform to a particular definition of professionalism, (3) navigating relationships between personal experiences with illness and patients' experiences, and (4) attempting to connect more closely with patients in small but meaningful ways. As we became clearer about the core construct of professionalism and these four themes, our theory of how they explain the ways that providers connect with patients and families began to develop.

Results: Development of a Relational Approach to Illness

Students across in all three disciplines described connections between their own experiences and those of their patients. Most students were slower to make these connections, and did not seem to initially recognize how their own experiences were currently impacting their work, making it more difficult for them to connect with patients. In this study, we will call this a "distanced approach" to illness wherein professional competence includes keeping safe emotional boundaries between self and patient. Other students – including at least one student from all three disciplines represented in this study - recognized these connections quickly, and seemed to use these commonalities as a way of connecting more closely with patients and families, taking what we call a more "relational" approach to illness. In other words, connecting more closely with one's own experience of illness seems to be a moderating experience that changed how students across disciplines ultimately defined professionalism. In the following, we will identify factors that distinguish students between these different views of professionalism.

Developing Professional Identities

Students in this study experienced a core tension between the healthcare culture of professional identities and the other aspects of their lives that challenged these evolving identities. This was particularly apparent in the medical and nursing student groups, and not as evident in the medical family therapy group. Students in the medical and nursing student groups reported being surprised by the differences between their expectations about what being a provider would be like and what their actual experiences were. They

quickly found themselves negotiating positions of power and hierarchy, and participants from both of these groups described developing a shell of privacy to cope with this. For these two groups, elements of professionalism seem to include the ability to maintain safe emotional boundaries between self and patient, and keeping one's personal matters private.

Medical family therapy students seemed to be developing a different definition of professionalism where making closer connections to patients and their experiences was natural and expected. Though MedFT students were also aware of maintaining "emotional safety" in connecting with patients, they appeared to feel more comfortable in making these personal connections. Students in this discipline repeatedly described situations in which they'd engaged in deep conversations with patients and families, had a difficult time moving on after their work was complete, and sought advice from supervisors and colleagues. In fact, we found only one medical family therapy student whose experience of professionalism mirrored comments by the medical and nursing student groups. In the following, she indicates a fear of letting emotions "get out of hand" in a way that seems unprofessional to her:

> Being around people who are really emotional and upset about somebody dying, I would just not be able to cry… it would just be too hard. Yeah, I don't think I'd be able to carry myself professionally in a setting like that.

Key factors in the difference between these groups seemed to be the training that students received on how to interact with patients and families and the emotional support that was given to them by mentors and supervisors when students found themselves getting in "too deep."

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Managing Expectations: Ideal Versus Lived Experience

Participants from all three disciplines, but especially medical and nursing students, reported disappointment on some level with the discrepancy between what they had imagined work as a healthcare provider would look like and the reality of their experiences (both academic and clinical) since beginning school. They repeatedly described frustration with the difference between the anticipated emotional connection students believed they would feel towards patients and families, and the reality of the challenges of this. In the following example, a medical student described this challenge (and later in the interview stated feeling hopeful that this might change in the future): "I don't know that I necessarily had clear-cut expectations for patient interactions, but I'm just more relational, like I said what I was drawn to . . . and that just doesn't really happen in the first two years."

Another medical student spoke about the role of emotion in her developing view of what it means to be a healthcare professional. She seemed to view emotionally connecting to her patients as being unprofessional:

> We're taught professionalism from day one, and I think many physicians that we follow and learn from have made that professionalism, or interpreted that as, um… like an emotional separation from their patients, which is healthy in some instances, but I think for me, that was hard to see.

This tension between the hope that students brought into their choice to pursue healthcare, and their lived experiences of quickly identifying that this did not seem to fit into the medical culture around "professionalism," appeared to be difficult for many of them. A number of participants from the medical and nursing student groups described being in the process of identifying why it was that most of their mentors maintained clear, non-emotional boundaries between self and patient. Several of them concluded that this

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was potentially harmful because it might be difficult to connect in this way to patients without becoming overwhelmed by their suffering.

The following medical student describes this type of intense, emotional connection to patients and families' experiences as being dangerous in a way: "I think it's possible to let every emotion have a full view, and not let it get out of hand… but as soon as I recognize that it's beginning to be too much, I stop it. It might begin to be too harmful."

While these sentiments were most often described in the medical and nursing student interviews, medical family therapy students also expressed being challenged by the heaviness of constant emotional work with patients and families. One student talked about the difficulty of empathizing with her patients, and how she coped with this through maintaining what felt like a safe emotional distance:

> It's really hard. Like I feel like I want to cry, but try not to cry. I try not to think about it. I think I cry because I put myself in their shoes too much, and I feel their pain… so it's really hard not to cry when I feel that. So [I] try to maintain some emotional distance from the situation.

Based on students' reflections, we saw several patterns beginning to develop. First, students often faced a discrepancy between what they anticipated healthcare work would be like and their actual lived experiences. Second, a significant challenge in making connections with patients and families seemed to be the emotional heaviness of this work, which was not always addressed by supervisors and colleagues and might not fit within a more distanced definition of professionalism. Third, this seemed to leave students feeling alone and unsure of how to manage their emotions when they were weighted down by these experiences.

Learning the Culture of Healthcare

Traditionally, the culture of healthcare has supported a clear distinction in roles

between providers and patients (Fox et al., 2011; McKevitt & Morgan, 1997). The

majority of our participants echoed this when they described coming up against power

and hierarchy in the healthcare system, experiencing pressure to conform to a more

distanced definition of professionalism, and coping with this tension by developing of a

shell of privacy.

Navigating Power and Hierarchy

Students from each discipline described a number of experiences through which

they quickly learned about the culture of healthcare, though these experiences differed

according to discipline. Those in the medical student group reported being surprised by

the "automatic" respect they received from patients, families, and other healthcare

providers. In the following, a medical student discusses this as both a privilege and a

responsibility: "You get a white coat, and people will tell you anything! It's unreal to me.

I'm still a medical student, but they'll call me doctor. It's a little scary." Another medical

student describes the power held in medicine in particular, when he states, "Because you

have an M.D. behind your name, you can kind of… you know, really get people

moving."

Along with power, learning to manage hierarchy within and between disciplines

seems to be an important part of healthcare culture. Nursing and medical family therapy

students seemed to feel this more, although medical students felt it within their own

discipline (i.e., with their mentors). One medical family therapy student describes feeling

like she had to "prove" herself and be a representative for her growing field when she stated: "Because we are such a new field and small field, I really get the sense that we are proving ourselves to the… medical field and other mental health fields." Another medical family therapy student echoes this when he says:

> I also think providers are different in just the general atmosphere of the facility… how well they receive MedFTs. This is just saying that there is a hierarchy between disciplines based on the provider a MedFT is working with and the validity of the job.

Nursing students also reported feeling surprised that were not receiving the type of support from those with more experience that they had anticipated. One student described this when she said, "I just didn't feel like they [other nurses] were very warm and kind… like nurses are supposed to be." Because they are not at the top of the healthcare hierarchy, nurses also face additional challenges in trying to appear competent and professional to providers from other disciplines. In the following example, a nursing student described connecting closely with a patient and family, only to feel that this could indicate to others how little time she'd spent in healthcare: "Other medical professionals, they might be like… Oh, they might have seen worse things, and [think that] I'm barely starting and what not. 'Oh, you're barely starting' or 'Don't take it seriously.'"

Within their own discipline, medical students also expressed coming to an understanding of hierarchy. Many of them described an atmosphere of watching and learning since questioning could be seen as disrespectful to those with more experience or higher up in authority. One medical student stated this hesitancy to question those with more experience clearly when she said, "We don't really question authority in healthcare." Another medical student described his frustration with feeling powerless, even with the power that he had as a medical student, within the larger healthcare system

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that felt out of his control:

> The red tape of the medical system will be really hard for me. I like working with the patients, and all of that, but I know that I will get frustrated by restraints that I'll have no control over… like hierarchy in the hospital, and trying to keep everybody happy, and doing a good job.

It was interesting for us to note that a number of the medical students described a hierarchy even within medicine itself, where students described certain specialties as being "on top" and others as being "on the bottom." One medical student stated, "Primary care is the least respected of all the specialties… family medicine and psychiatry too." Another student echoed this by saying, "Family medicine, peds, psychiatry, preventative medicine… they're all at the bottom."

Although it may have been in different ways, most study participants described a similar theme of being surprised and challenged by the strength of power and hierarchy within the healthcare system. As students, this was especially difficult for them, although medical students reported already being respected by other providers and patients as they began wearing their white coats.

> I've heard so many classmates that when they're doing their psychiatry rotation they're like, 'Yeah! I think I'm going to do psychiatry! It's awesome.' And then they get out of it [psychiatry rotation], and I feel like they don't have the guts to choose it any more.

This indicated to us that students often began their rotations through specialties like psychiatry and family medicine with a high interest, only to feel significant pressure to choose another area more highly respected by others. In our own work as medical family therapists, it has seemed that generally those in psychiatry and family medicine seem more comfortable interacting with patients and families in a more relational way. Therefore, we were especially interested that these were the disciplines that students

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already felt pressure to move away from.

Developing a Shell of Privacy

Another important theme in healthcare culture seemed to be keeping one's personal problems quiet. This was especially salient to those in the medical student group. In the following example, a medical student described having struggled with depression while in the program and the understanding she has of being in a culture where this is not talked about: "What it comes down to is that I wouldn't go blabbing it to the world, because no one in my program really talks about that kind of thing." When asked if or whom she might talk to while going through personal problems in her program, another medical student stated, "What's intuitive to me is not to talk to anyone in my professional environment." Another medical student discussed relying on her own support system, rather than anyone in her discipline, to cope with personal difficulties: "It's not something that happens very often. People don't really talk about those more emotional things in medicine. It seems like everyone just tries to deal with that themselves or with their families."

These student reflections indicated several things to us. Medical and nursing students who personally experienced illness seemed to have difficulty integrating this into their developing identity around what it means to be a healthcare professional. When these students experienced frustration in working with a patient or family who trigger something for them, they most often coped with this by themselves or with a trusted person outside of their professional circle. This was different than the medical family therapy group, where students repeatedly expressed the availability and comfort

they felt in going to supervisors and colleagues with the more emotional aspects of providing care for patients and families.

Illness Narratives

All of the students we interviewed had experienced illness in some way – either through personal experience, or by having a close friend or family member go through this. We were interested to see if or how students connected these experiences with having any impact on their work, and found that most of them did not initially make this link. In the following example, a nursing student described her family's experience with illness early in the interview:

> My other Uncle has Type II Diabetes because he's overweight. And I know he has underlying things, I know he's gone to a doctor and got diagnosed with a thyroid issue. But you know, I see some people who are just extremely overweight, and I think "there's got to be something else."

Later in the interview, we asked her what types of patients she thinks she might be challenged in working with. She stated: "Specifically what I would have a hard time with is people who don't take care of themselves." Though she did not directly make the link between her family's experience with illness and her clinical work, it seems clear that because of her family's personal experience with this, it is a challenging area for her.

While most students did not initially make the connection between personal experience and populations of patients or families that they have an easier or more difficult time connecting to, there were a few exceptions. We asked a medical student early in our interview what types of patients she connected most closely with, and she replied: "Specifically people with chronic diseases, I can connect with. Because I've known people with that, and I kind of know where they're coming from. I feel it's easy to

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empathize with them." In this example, the student had coped with Crohn's disease for many years, and immediately recognized her own connection to her patients' experiences with chronic illness. Interestingly, she seemed to have found that it is a resource, rather than a hindrance, for her in relating more closely with them.

Conversely, one of the medical family therapy students was also an exception in that he didn't seem to clearly link his own experiences with any biases or inclinations towards current work with patients and families. When asked, "How do you think these experiences [with personal illness] influenced how you approach people dealing with illness?" he responded with, "I'm not sure they had… If I think about [these experiences], I don't have a thought of the connection or one that really jumps out at me." This student still emphasized the importance of connecting with patients and families, but it was the academic and supervisory support that he had available to him that seemed to be most influential.

Relational Perspectives

Developing Connections with Patients and Families

As a whole, medical family therapy students appeared to be much more comfortable taking a relational approach to illness; that is, to make personal connections with patients and families part of their definition of professionalism. In the following examples, medical family therapy students described why these connections were important to their work, and conveyed a sense of confidence in including them in care: "I think it's incredibly valuable to have as many subsets of the whole system as we can around that patient to talk to; to work with." Another student said, "I love working with

families. To bring another person into the room makes the work richer." In the following, a MedFT student described families as a resource, rather than a hindrance, to care when she said, "I'm always glad when families are there. Just because of my relational perspective of MedFT, I think the family can be a great resource."

Medical and nursing students who seemed to connect more closely with their own illness narratives were also quick to connect this to their current work with patients and families. This awareness of the impact of their illness narratives on their own lives (and onto the lives of family, friends, and communities) seemed to expand their developing definitions of professionalism. Students who described the impact of their own experiences on their current work as being too salient to ignore talked about professionalism as including these relational connections. These students responded to this by making purposeful efforts to convey care to patients and family members in meaningful ways.

In the following example, a nursing student described an experience that was not helpful to her and her family after her father was hospitalized, and the immediately recognized the impact that this had on the way that she would like to relate to patients and families:

> I was kind of angry at the nurses… they kind of isolated us. They kind of made my dad feel lonely. I want to be conscious about the way that I'm treating patients. I just want to make sure that I make a difference, you know? That when I go into the room, they can actually tell that I care about them.

Clearly, this experience impacted the participant and continues to affect the way she thinks about the work that she does with patients.

Among medical and nursing students this was a minority group; most of the participants had difficulty making this connection, and responded at first with statements

indicating that they were unsure of if or how their own experiences impact the way they

think about healthcare or including patients' family members in care. However, a

number of these students became aware of this connection during our interview process.

For example one medical student stated, "I've never really experienced illness, and no

one in my family has either." Towards the end of the interview, she recalled the pain she

felt when her grandmother was going through difficult medical complications, and how

this related to the present challenges that presently she has in working with geriatric

patients:

> My grandma has had chronic back pain and head pain, and she's tried numerous
> little things to feel better and to be pain-free. So I think that probably influences
> what I said in the beginning about geriatrics… just seeing, you know, the trouble
> that she's had. So yeah… It's so funny, because I think my grandma has
> definitely affected my view of end-of-life care.

Conveying Care

Even with the time constraints that healthcare providers face, participants with a

more relational definition of professionalism reiterated the importance of conveying care

in manageable ways. In the following example, a nursing student described how she

makes efforts to share small moments with patients and their families:

> So if I can just help out a little bit… make their experience more positive, even if
> it's only a small amount that might not even be, like, tangible… I think it's worth
> it. Just sharing a smile. Just doing little things to make it more comfortable.

Another nursing student echoed this when she answered a question about how she

shows patients and families the care that she's referring to as being important: "It's just

hanging out with them and talking with them." Even with the limited time frame that

providers are often working within, some students seemed to make these connections a

purposeful part of their interactions with patients. A medical student described how she attends to this when she says, "While treating the body, I can touch on heart issues as well." In these small but meaningful ways, these participants seemed to be finding a balance between being seen as a professional, and also connecting with patients in ways that were both manageable and meaningful.

In summary, students' illness narratives seemed to offer them an expanded definition of what it means to be a professional. Those students who connected closely with their own illness narratives seemed to want to care for patients and families in more relational ways, as this had either been helpful to them in their own experiences, or is something they wish had been done at that time. These narratives were too important for students to overlook; instead, they used them as a way to relate more closely to patients. Even when participants were faced with common frustrations, such as time management and the larger culture of healthcare, those students who were impacted by their own experiences found ways to convey relational care to patients and families through small acts of connection and communication.

Discussion

In this dissertation, we set out to understand how healthcare providers' own experiences impact their work with patients and families. Through this process, we developed a grounded theory explaining how providers own experiences impact their definitions of professionalism and in particular, the distant or relational ways that they connect to patients and families. This study is unique in that it highlights the construction of professionalism and how this definition may differ across disciplines based on

training. Medical and nursing student participants appeared to emphasize a discourse of competence as being key to what it means to be a professional. This definition includes an emphasis on proficiency in technical skills and the ability to be objective and to maintain professional distance. In contrast, medical family therapy participants were more focused on relational care as the most important aspect of professionalism.

Understanding differences between these definitions of professionalism and how they impact providers' abilities to connect with patients and families is important in several ways. First, it demonstrates the potential for growth and flexibility related to developing views of professionalism. For our participants, these definitions were not set in stone, but instead were continuing to be shaped by their current training, support by mentors and colleagues, and interactions with patients and families. Second, it highlights implications for medical family therapists in understanding how providers from other disciplines may have different definitions of professionalism based on competence. This is important if medical family therapists want to work with providers around developing a more inclusive, relational view of professionalism, as it may be helpful to frame this as "care as competence."

Development of Theory

In developing this grounded theory, we began by looking for how providers' personal experiences with illness impacted their clinical work, and particularly how they chose to include patients' families in care. We found that the majority of medical and nursing student participants described a tension between how they viewed professionalism and how they wanted to connect with patients and families. For these

disciplines, developing a definition of professionalism based on competence seemed centered around four significant processes: (1) facing discrepancies between ideals around being a healthcare provider and students' lived experiences, (2) coping with the challenges of healthcare culture, (3) navigating relationships between own experiences with illness and patients' experiences, and (4) attempting to connect more closely with patients and their families.

Medical family therapy students seemed to have a different, more relational, definition of professionalism. For these participants, connecting closely to patients and families was seen as a key part of being a professional. While medical and nursing students often described developing a "shell of privacy" to keep personal and professional struggles separate, medical family therapy students expressed feeling support by supervisors and colleagues around talking about self-of-the-provider concerns and the heaviness of emotionally connecting to patients and families. These participants seemed to quickly and easily connect the impact of their personal experiences with illness on their current clinical work. In other words, they made purposeful efforts to provide small acts of care for patients and families that were either meaningful for the providers themselves when they were ill or reflected the type of care that they wished they had received.

Care as Competence

Given the results of this study, we may conclude that different disciplines in healthcare emphasize different aspects of professionalism. For medical and nursing students, an important component of this is competence in caregiving. This is consistent

with a recent study of medical students (Lingard, 2009) in which the researcher writes, "Discourses of competence are especially important in medical education." The development of technical knowledge and familiarity with skills is a necessary part of their work, as providers' jobs are on the line if they don't have the right answers (MacLeod, 2011). While MedFTs also struggle to find a definition of professionalism (Bischof, Lieser, Taratuta, & Fox, 2003), training for these students appears to include more of an emphasis on self-of-the-provider reflection and support for making close connections to patients and families.

If healthcare providers want to embrace family-centered care, it may be useful to consider how training can better prepare students for these relational aspects of their work by framing this as "care as competence." In this way, students will be challenged to conceptualize joining with patients and actively including families in care as part of their developing definitions of professionalism. Attending to providers' own illness narratives is a key first step important piece in this, as these narratives affect the formation of both personal and professional identity (Browning et al., 2011). Interdisciplinary training that supports providers across disciplines in reflecting on their own experiences with illness and making connections between these experiences and the work they do now, may result in better support for providers and better care for patients and families.

Implications

Although previous researchers have found that clinicians' beliefs about healthcare impact the way they work with patients and families (Griffith & Griffith, 1994; McDaniel, Hepworth & Doherty, 2003), there is still a need for continued growth in

translating this into students' training programs. We believe that this study is another

step in expanding the existing knowledge base about the impact of providers' personal

experiences on care given to patients and families, and hope that it will be particularly

helpful for healthcare instructors and those who are leading interdisciplinary healthcare

trainings. Medical family therapists are in a unique position to take part in this, as our

role is often a bridge between patients and providers.

It was clear to us that students from all three disciplines want to connect with

patients and families; however, many of them felt ill-equipped to do so. One medical

student who seemed heavily impacted by her own family's experience with illness

described purposefully seeking out a mentor who would help her with the more relational

aspects of care. When asked if this was a part of her training, she replied, "It's definitely

something that I've learned, but I'm not sure that it's something that I've learned in this

program." Things that her mentor coached her on included "learning how to make that

(including families) part of the interview process," and "figuring out how they're feeling

about it and what impact this is having on them."

Interdisciplinary training may be useful in routinely helping students to develop

these kinds of joining skills. Medical family therapists are in a unique position to

collaborate with students and healthcare providers about their experiences with patients

and families, normalize concerns and frustrations, and offer support to those who would

like to connect more closely with patients and their families. Practical examples of

training interventions might include asking students to write their own illness narratives,

interdisciplinary workshops where participants can practice enactments in learning how

to talk with patients and families (Browning et al., 2011), asking students to partner with

a patient or family and journal about what they are learning and what this experience might be like for them (White, Perlman, Fantone, & Kumagai, 2010), or having students write "parallel charts" on their patients' non-medical experiences with illness (Brett-Maclean, Cave, Yiu, Kelner, & Ross, 2010).

In order to collaborative with other disciplines effectively, it may additionally helpful for medical family therapists to have a better understanding of how providers from other disciplines conceptualize professionalism. There are a number of reasons that most healthcare providers maintain a "safe balance" approach to connecting emotionally with patients and families. Healthcare providers constantly find themselves in the position of negotiating a balance between self and other. They must attend to the needs of patients and families, which often involves the heavy emotional work of delivering bad news, dealing with frustrated or angry patients, and witnessing death and dying. At the same time, they must attend to the needs of self: compartmentalizing or practicing other acts of self-care that keep patients' experiences from overwhelming them. If this balance shifts too much in one direction or another, healthcare providers may face a number of negative consequences (Burks & Kobus, 2012), including emotional fatigue and burnout.

Some of the common work demands that healthcare providers face include long working hours (especially for those in medicine), feeling a lack of autonomy or ability to make decisions for oneself within the larger medical system, and imbalances between time and effort spent at work and home, which may additionally result in poorer social support systems (Burks & Kobus, 2012). In conjunction with these stressors, expecting providers to demonstrate high levels of empathy for patients and families may be too overwhelming.

It seems important then for medical family therapists to understand how and why healthcare providers may have different definitions of professionalism, and may have concerns about giving too much emotionally to patients and families. In our own experiences working with healthcare providers from a variety of disciplines at a large, 815-bed Southern California hospital, we have found ourselves surprised by the weight of the burden that providers already face. With time spent working collaboratively together, it has become more apparent to us that in order for us to work effectively, we cannot expect that providers become therapists with patients in addition to the work that they already do. Instead, it has been useful for us to provide collegial support and concrete, behavioral suggestions for providers who want to connect with patients and families while still maintaining personal balance.

If providers from other disciplines emphasize competence as the most important part of being a professional, medical family therapists can work with them to help support "care as competence." Although there are many ways that this could be done, one example might be having medical family therapy students work with medical and nursing students in interdisciplinary training workshops on delivering bad news to patients and families. This format would mirror competency-based trainings, such as "OSCE's," or Objective Structured Clinical Examinations, often included in healthcare education, but with a specific focus on the importance of conveying care as a skill to be developed.

Limitations

There are several limitations to this study. First the sample was mostly female

(27 women, 3 men). How gender may influence perceptions of relational connection still needs to be examined. It is also unclear how the religious affiliations of the institutions from which students were invited to participate may shape the development of professional identities. In addition, due to systemic privilege that generally allows White people easier access to higher education, fewer students of color are represented. Lastly, although nurses, physicians, and medical family therapists make up a significant sample of workers in healthcare, we were not able to include participants from other healthcare disciplines. Those in such fields as physical and occupational therapy, nutrition, pharmacy, and social work may find similarities or differences in their own narratives and how these impact their work with families.

Future Directions

We hope that future research will highlight training facilities offering self-of-the-provider reflection and interdisciplinary collaboration, including the development of these programs and how effective they are at helping students learn to think relationally about illness. Additionally, in our own research for this study, we found that a number of women in both medical and nursing student groups reported gender as being a significant challenge to connecting with men in healthcare (both patients and providers). A female medical student describes the hesitancy that she feels in speaking out too much when she states, "I don't want to draw unwanted attention." We were not specifically asking about or looking for gendered issues in this study, but because of these findings, we believe there is further research to be done on the experiences of women working within a hierarchical healthcare system.

Throughout this study, what stood out most to us was how deeply students wanted to connect with patients and families, and how simultaneously uncertain they felt in having the skills to do so. This highlighted the importance of providing students with as many opportunities to practice these skills as possible, and caused us to consider how medical family therapists might be in a unique position to offer help in this process. Relationship-centered care has been shown to be helpful in a number of ways for patients (Burg & Seaman, 1994; Marriott, Donaldson, Tarrier, & Burns, 2000; Mueser et al., 2009), for family members (Martire, 2005), and for providers themselves (Sawa, 1998; Harkness & Nofziger, 1998), and we hope that future research will more concretely show how this can and is being addressed across disciplines.

CHAPTER SEVEN

EXPANDED DISCUSSION AND IMPLICATIONS

Discussion

Providers' Professional and Personal Identities

The development of professional identity typically starts early on for most healthcare providers. MacLeod (2011) writes, "Medical education is the process by which learners develop professional identities and begin to engage with the multiple discourses that constitute the institution of medicine." Over the past several decades, understanding of the development of professional and personal identities has shifted from belief in separate, contained identities towards a more multi-faceted approach (Kram, Wasserman, & Yip, 2012). Underlying our identities are constantly-developing values, goals, priorities, and beliefs about who we should be in the world (Kram, Wasserman, & Yip, 2012). Because identities often overlap, it is not uncommon for healthcare professionals to experience conflict between them and to feel confused about how to manage these conflicts (Osteen, 2011).

Healthcare developed from the medical model has traditionally embraced a clear role division between patient and provider (Fox et al., 2011; McKevitt & Morgan, 1997). This can create difficulty for healthcare providers when personal and professional identities overlap or when they experience conflict between different identities. Providers who share with colleagues something they know from personal experience may be perceived as unprofessional (Browning et al., 2011), reflecting the underlying, socially-constructed value that providers should have knowledge not from personal experience on the receiving end of healthcare, but from a separate place of expertise.

Because self-of-the-provider reflection isn't always a strong focus of healthcare

providers' training (McDaniel, Hepworth, & Doherty, 1992), students may find

themselves uncomfortable connecting too closely with patients' experiences, fearing that

this may make them "less professional" in some way (McKevitt & Morgan, 1997).

Maintaining Safe Balance

There are a number of reasons that most healthcare providers maintain a "safe

balance" approach to connecting emotionally with patients and families. Burks and

Kobus (2012) state:

> The tendency to view and discuss patients in objective, technical, detached
> and non-humanistic ways often occurs in the culture of medicine. This does
> not imply unkindness, but, rather, has developed for beneficent purposes,
> such as the provision of scientific expertise and efficient communication.

Healthcare providers constantly find themselves in the position of negotiating a

balance between self and other. They must attend to the needs of patients and families,

which often involves the heavy emotional work of delivering bad news, dealing with

frustrated or angry patients, and witnessing death and dying. At the same time, they must

attend to the needs of self: compartmentalizing or practicing other acts of self-care that

keep patients' experiences from overwhelming them. If this balance shifts too much in

one direction or another, healthcare providers may face a number of negative

consequences (Burks & Kobus, 2012), including emotional fatigue and burnout.

Some of the common work demands that healthcare providers face include long

working hours (especially for those in medicine), feeling a lack of autonomy or ability to

make decisions for oneself within the larger medical system, and imbalances between

time and effort spent at work and home, which may additionally result in poorer social

support systems (Burks & Kobus, 2012). In conjunction with these stressors, expecting providers to demonstrate high levels of empathy for patients and families may be too overwhelming.

It seems important then for medical family therapists to understand how and why healthcare providers may have different definitions of professionalism, and may have concerns about giving too much emotionally to patients and families. In our own experiences working with healthcare providers from a variety of disciplines at a large, 815-bed Southern California hospital, we have found ourselves surprised by the weight of the burden that providers already face. With time spent working collaboratively together, it has become more apparent to us that in order for us to work effectively, we cannot expect that providers become therapists with patients in addition to the work that they already do. Instead, it has been useful for us to provide collegial support and concrete, behavioral suggestions for providers who want to connect with patients and families while still maintaining personal balance.

Implications

Medical Family Therapists

We hope that medical family therapists will seek out additional opportunities to learn about the training that healthcare providers go through, what's important to them in being seen as a professional, and how finding a balance between giving to patients and families and "staying afloat" is so challenging. It may be useful for medical family therapists to ask to sit in on classes for physicians or nurses in training, especially during the last several years when students are actively involved in learning technical skills *and*

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trying to apply these through good interactions with patients and families. For example, sitting with nursing students as they learn about the difficulty of placing catheters while attempting to maintain patients' dignity and privacy at the same time may provide MedFTs with a different perspective on the many demands that nurses face.

It may be even more useful for medical family therapists to shadow providers; not just for an afternoon, but for several days or even a week. In her own training, the first author followed a psychiatrist during a day on call at the hospital and was amazed by the physical, mental, and emotional toll that this took. Together, we were often rushing from room to room and floor to floor, standing for hours on end without a break, attempting to locate patients' charts, being stopped in the hallway and asked for recommendations, and interacting with anxious and distressed patients and families. As I talked with this psychiatrist about how he continued with this day after day, his response mirrored what is found in the literature: it was difficult, and often felt to him as though he was caught in between situations with no good way out. This experience shifted the relationship between us, to where I now began to appreciate the enormous number of responsibilities he faced, and the attempts that he made to balance these with his own needs.

Interdisciplinary Collaboration

These considerations in both our own experiences and in the literature fit with what students in this study reported. Many of them wanted to connect more closely to patients and families, but felt uncertain of how to do so, and ill-equipped to manage the balance between self and other. Medical family therapists may be helpful in supporting healthcare providers to manage these tasks in a number of ways, including working with

providers to demonstrate and practice small, behavioral skills to communicate more effectively with patients and families.

One of the ways that we found ourselves doing this was through a weekly meeting with the psychiatry team and medical residents and students. During these several hours each week, we would do joint rounds with mutual patients we were caring for. This time was informative for all of us: we learned a great deal about how the psychiatry team worked, how assessments were completed, medications considered, and time managed. In short, videotaped interviews, we asked the psychiatry team and a number of medical residents and students what was helpful for them about this collaborative experience, and they replied that it was eye-opening for them to watch us make meaningful connections with patients in a relatively short amount of time. This challenged their ideas about making connections with patients and providers, and was a good opportunity for us to demonstrate specific skills that many of them asked us about and then began to try on their own.

For example, one of the residents inquired how we might respond to a patient who becomes emotional. Together, we talked about specific, behavioral tasks, such as pulling up a chair next to the patient (rather than standing around the bed as is usually done in hospital settings), leaning in so that the patient can see that we are listening, and making short reflections on the emotion, such as: "I can see that this has been really difficult for you." The resident asked, "What then? What if they keep talking about that and I have to go? How do I wrap that up?" In response, we discussed how patients and families often report to us how meaningful it is to have providers acknowledge their suffering, even if for just a few moments, and even without a "solution" readily available, and how it may

be helpful to say something like, "I appreciate you sharing this with me, and I'll be checking in with you tomorrow to see how things are going then."

Mentoring providers through learning relational skills in this way may be thought of as teaching "care as competence," where providers are seeing these ways of connecting as skills that can be learned through practice and with support, and that will benefit them in fulfilling the meaningful nature of their work without overwhelming them. Framing relational skill-building in these concrete, behavioral ways may help healthcare students and educators to view empathy towards patients and families not as a "soft science or a touchy-feely idea" (Burks & Kobus, 2012), but as a set of scientific skills that may benefit providers in their clinical work, their personal lives, and their professional development (Boutin-Foster, Foster, & Konopasek, 2008; Shapiro, Coulehan, Wear, & Montello, 2009).

Interdisciplinary Training

Participants in our study indicated that one way in which they were able to make more purposeful connections with patients and families was by recognizing that their personal experiences with illness were impactful not only to them, but to their families, friends, and communities as well. Students who connected closely to their own experiences seemed to have a different definition of professionalism, and were able to make closer connections with those they were caring for. This was similar to what we were mentoring psychiatry residents and medical students on: making connections in small, manageable ways, such as inviting family members into care, sharing a smile, or acknowledging the pain or difficult decisions patients were facing.

It may be useful for medical family therapists to seek out opportunities for interdisciplinary training with other providers. For example, medical family therapists, as well as physicians and nurses, would likely benefit from participating in a reflection of how personal experiences impact our work. Students from all three of these disciplines could write their illness narratives, and then share them in a group format during a workshop that could serve as one class period in an overlapping area; for example, medical family therapists' education on self-of-the-provider, nursing students' education in family nursing, and medical students' training in OSCE (Objective Structured Clinical Examination) demonstrations. Going through these exercises together would help inform students from all disciplines about the training and work that others do, and would additionally provide medical family therapists with a better understanding of the ways that we might support providers from other disciplines.

Supporting providers across disciplines in self-reflection and learning how to connect more closely with patients and families may be useful in a number of ways. Research shows that interdisciplinary, collaborative care is cost-effective (Katon et al., 2006), and that providers who collaborate openly with other clinicians have patients reporting significantly higher levels of satisfaction with their medical care (Deen, Fortney, & Pyne, 2011). Patients receiving collaborative care also demonstrate higher levels of physical improvement across a variety of illnesses, including better management of blood sugars for patients struggling with diabetes (Arevian, 2005), greater long-term depression outcomes (Lin et al., 1999), and improved pain management (Dobscha et al., 2009).

It seems clear that promoting self-of-the-provider reflection and learning how to connect with patients and families in small, concrete ways may be beneficial for patients, families, and providers themselves. Medical family therapists are in a unique position to take part in these processes, but must first understand how and why the culture of healthcare is different than the culture of training that family therapists are often educated within. We hope that additional medical family therapists and training programs will highlight ways in which they are learning about the culture of healthcare, finding ways to support providers in making empathic connections to patients and families through concrete, behavioral skill-building, and supporting providers in caring for themselves through these processes.

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SCHEDULE OF QUESTIONS: NURSING STUDENTS

This is a study that will help us learn more about you and your family's experience with illness as well as informing us about your experiences in learning about and providing family-centered care. We will ask you a series of questions that are worded in such a way to help you think out loud about some issues. There are no right or wrong answers—we are interested in learning how you think: your opinions, experiences, and your unique ideas. Please take your time answering these questions.

We will start with a few brief questions that will help us understand you a bit better:

1. What first interested you in nursing?

2. What area of nursing are you most interested in?

3. What drew you to this population?

4. What area of work is most difficult for you? Why?

5. How was nursing school similar to or different than your expectations?

6. What were the challenges you faced in nursing school?

7. How did you cope with those challenges?

8. As nurses, we often find ourselves connecting with certain patients and relating to their lives. Has this ever happened to you? Could you tell us about that experience?
a. What were the positives of empathizing with this patient/family?
b. What were the negatives of empathizing with this patient/family?

9. Have you recognized a situation in a patient/family that reminded you of a situation in your own life (past or present)?
a. If so, what were your thoughts and feelings on a personal level? How did that affect your work with the patient/family?
b. If not, what eventually led you to see your connection to the patient?

10. What were your thoughts and feelings looking back on that time?

11. What were the general attitudes towards illnesses, hospitalizations, disabilities, injuries, and death in your family?

12. What recollections do you have of yourself/family member/close friend experiencing illness?

a.   What were your thoughts and feelings about that experience then?
b.   What are your thoughts and feelings about that experience now?
c.   What would have been helpful for you and your family at that time?

13. In what ways did that experience impacted you personally and/or professionally?
a.   How do these ideas influence the way you approach people with illness?
b.   How do these ideas influence your attitudes or approach toward healthcare and healthcare workers?

14. What strengths do you have as a result of going through that experience that may impact how you intervene with people who have medical or health concerns?

15. When you began clinical work, what was your experience in interacting with patients' families?

16. Did you feel prepared to include them in your plan of care?
a.   If not, what would have been helpful to you in feeling more confident in this area?
b.   If so, what was helpful to you in feeling confident in this area?

17. Have you noticed changes in how you include or avoid patients' families in the time since you began nursing? If so, what do you attribute those changes to?

18. When you experience frustration in working with a patient or family, to whom do you turn to for advice or a listening ear?
a.   What has been helpful about talking with others?
b.   What has not been helpful about talking with others?

19. Is there anything else that you would like for us to know that would help us understand how your own experience with illness has impacted your work as a nurse?

20. Is there anything else that you would like for us to know that would help us understand your perspective on working with patients' families?

21. Is there anything else that you would like to share with us that we did not ask?

SCHEDULE OF QUESTIONS: MEDICAL STUDENTS

This is a study that will help us learn more about you and your family's experience with illness as well as informing us about your experiences in learning about and providing family-centered care. We will ask you a series of questions that are worded in such a way to help you think out loud about some issues. There are no right or wrong answers—we are interested in learning how you think: your opinions, experiences, and your unique ideas. Please take your time answering these questions.

We will start with a few brief questions that will help us understand you a bit better:

1. What first interested you in medicine?

2. What area of medicine are you most interested in?

3. What drew you to this population?

4. What area of work is most difficult for you? Why?

5. How was medical school similar to or different than your expectations?

6. What were the challenges you faced in medical school?

7. How did you cope with those challenges?

8. As healthcare providers, we often find ourselves connecting with certain patients and relating to their lives. Has this ever happened to you? Could you tell us about that experience?
a.   What were the positives of empathizing with this patient/family?
b.   What were the negatives of empathizing with this patient/family?

9. Have you recognized a situation in a patient/family that reminded you of a situation in your own life (past or present)?
a.   If so, what were your thoughts and feelings on a personal level? How did that affect your work with the patient/family?
b.   If not, what eventually led you to see your connection to the patient?

10.   What were your thoughts and feelings looking back on that time?

11. What were the general attitudes towards illnesses, hospitalizations, disabilities, injuries, and death in your family?

12. What recollections do you have of yourself/family member/close friend experiencing

illness?
a.   What were your thoughts and feelings about that experience then?
b.   What are your thoughts and feelings about that experience now?
c.   What would have been helpful for you and your family at that time?

13. In what ways did that experience impacted you personally and/or professionally?
a.   How do these ideas influence the way you approach people with illness?
b.   How do these ideas influence your attitudes or approach toward healthcare and healthcare workers?

14. What strengths do you have as a result of going through that experience that may impact how you intervene with people who have medical or health concerns?

15. When you began clinical work, what was your experience in interacting with patients' families?

16. Did you feel prepared to include them in your plan of care?
a.   If not, what would have been helpful to you in feeling more confident in this area?
b.   If so, what was helpful to you in feeling confident in this area?

17. Have you noticed changes in how you include or avoid patients' families in the time since you began nursing? If so, what do you attribute those changes to?

18. When you experience frustration in working with a patient or family, to whom do you turn to for advice or a listening ear?
a.   What has been helpful about talking with others?
b.   What has not been helpful about talking with others?

19. Is there anything else that you would like for us to know that would help us understand how your own experience with illness has impacted your work as a nurse?

20. Is there anything else that you would like for us to know that would help us understand your perspective on working with patients' families?

21. Is there anything else that you would like to share with us that we did not ask?

SCHEDULE OF QUESTIONS: MEDICAL FAMILY THERAPY STUDENTS

This is a study that will help us learn more about you and your family's experience with illness as well as informing us about your experiences in learning about and providing family-centered care. We will ask you a series of questions that are worded in such a way to help you think out loud about some issues. There are no right or wrong answers—we are interested in learning how you think: your opinions, experiences, and your unique ideas. Please take your time answering these questions.

We will start with a few brief questions that will help us understand you a bit better:

1. What first interested you in medical family therapy?

2. What area of work are you most interested in?

3. What drew you to this population?

4. What area of work is most difficult for you? Why?

5. How was medical family therapy similar to or different than your expectations?

6. What were the challenges you faced in nursing school?

7. How did you cope with those challenges?

8. As medical family therapists, we often find ourselves connecting with certain patients and relating to their lives. Has this ever happened to you? Could you tell us about that experience?
a.   What were the positives of empathizing with this patient/family?
b.   What were the negatives of empathizing with this patient/family?

9. Have you recognized a situation in a patient/family that reminded you of a situation in your own life (past or present)?
a.   If so, what were your thoughts and feelings on a personal level? How did that affect your work with the patient/family?
b.   If not, what eventually led you to see your connection to the patient?

10.   What were your thoughts and feelings looking back on that time?

11. What were the general attitudes towards illnesses, hospitalizations, disabilities, injuries, and death in your family?

12. What recollections do you have of yourself/family member/close friend experiencing

illness?
a.   What were your thoughts and feelings about that experience then?
b.   What are your thoughts and feelings about that experience now?
c.   What would have been helpful for you and your family at that time?

13. In what ways did that experience impacted you personally and/or professionally?
a.   How do these ideas influence the way you approach people with illness?
b.   How do these ideas influence your attitudes or approach toward healthcare and healthcare workers?

14. What strengths do you have as a result of going through that experience that may impact how you intervene with people who have medical or health concerns?

15. When you began clinical work, what was your experience in interacting with patients' families?

16. Did you feel prepared to include them in your plan of care?
a.   If not, what would have been helpful to you in feeling more confident in this area?
b.   If so, what was helpful to you in feeling confident in this area?

17. Have you noticed changes in how you include or avoid patients' families in the time since you began clinical practice? If so, what do you attribute those changes to?

18. When you experience frustration in working with a patient or family, to whom do you turn to for advice or a listening ear?
a.   What has been helpful about talking with others?
b.   What has not been helpful about talking with others?

19. Is there anything else that you would like for us to know that would help us understand how your own experience with illness has impacted your work as a nurse?

20. Is there anything else that you would like for us to know that would help us understand your perspective on working with patients' families?

21. Is there anything else that you would like to share with us that we did not ask?

INVITATION TO PARTICIPATE: LLU

CURRENT ISSUES IN HEALTHCARE: PROVIDING FAMILY-CENTERED CARE AND EXPLORING ILLNESS NARRATIVES

Dear Student,

We'd like to invite you to participate in a research study on the challenges that healthcare providers face in their work, and some of their personal experience with illness. It is conducted by Dr. Barbara Couden Hernandez, Ms. Lindsey Lawson, and Carmen Knudson-Martin of Loma Linda University in Southern California. Both of us are nurses as well as marriage and family therapists. There are no current studies on our topic. By participating, you will be helping us to discover the first research findings about some of the reasons people choose to study medicine, and how medical students make clinical decisions.

This study is not part of your department and whether you participate or not will in no way affect your standing in your program. We have explained the study to the Chair of your program regarding this study and he/she has consented to forward our invitation to participate on to you. That is the extent of your professors' involvement with this study. We will not tell your faculty whether you participate or not, nor will we share anything with them that you tell us in the interview.

If you would like to participate in this study, you will be asked to have an interview with a member of our research team. The interview will last between 60 – 90 minutes depending on what you want to share with us. The conversation will be tape recorded and transcribed into a written document. The tapes will then be destroyed so no one else will have them. All names, and references to places, people, and in some cases, other occupations, will be changed or removed in order to decrease the likelihood that you could be identified based on your comments. Your interview will be added to a group of other interviews and analyzed collectively. We plan to publish our findings after we analyze what everyone tells us. When anyone reads our study they will not be able to identify you since we will change the information that could identify you to anyone else.

If you would like to take part in the study, or if you have any questions about it, you may call either one of us for more information. Our phone numbers are given below. Please reply by email or phone to either of us. We will contact you and arrange a time for an interview that is convenient for both of us. You will have the right to end the interview at any time if you start and then think that you might not want to finish the interview. If you complete the interview, you will be given a $25 gift card of your choice to either Chipotle or Starbucks.

We appreciate your willingness to talk with us and are excited to hear what you have to

teach us about your experience.
Thank you for considering this opportunity to help the field of healthcare.

Barbara Couden Hernandez, Ph.D., LMFT, RN
bhernandez@llu.edu (909) 558-4730)

Lindsey Lawson, M.S. MFT, RN
lalawson@llu.edu (206-769-7419)

Carmen Knudson-Martin, Ph.D., LMFT
cknudsonmartin@llu.edu

CURRENT ISSUES IN HEALTHCARE: PROVIDING FAMILY-CENTERED CARE AND EXPLORING ILLNESS NARRATIVES

Dear Student,

We'd like to invite you to participate in a research study on the challenges that healthcare providers face in their work, and some of their personal experience with illness. It is conducted by Dr. Barbara Couden Hernandez, Ms. Lindsey Lawson, and Dr. Carmen Knudson-Martin of Loma Linda University in Southern California. Both of us are nurses as well as marriage and family therapists. There are no current studies on our topic. By participating, you will be helping us to discover the first research findings about some of the reasons people choose to study medical family therapy and how medical family therapists make clinical decisions.

This study is not part of your department and whether you participate or not will in no way affect your standing in your program. We have explained the study to the Chair of your program regarding this study and he/she has consented to forward our invitation to participate on to you. That is the extent of your professors' involvement with this study. We will not tell your faculty whether you participate or not, nor will we share anything with them that you tell us in the interview.

If you would like to participate in this study, you will be asked to have either a telephone or Skype interview with a member of our research team. The interview will last between 60 – 90 minutes depending on what you want to share with us. The conversation will be tape recorded and transcribed into a written document. The tapes will then be destroyed so no one else will have them. All names, and references to places, people, and in some cases, other occupations, will be changed or removed in order to decrease the likelihood that you could be identified based on your comments. Your interview will be added to a group of other interviews and analyzed collectively. We plan to publish our findings after we analyze what everyone tells us. When anyone reads our study they will not be able to identify you since we will change the information that could identify you to anyone else.

If you would like to take part in the study, or if you have any questions about it, you may call either one of us for more information. Our phone numbers are given below. Please reply by email or phone to either of us and we will send you an informed consent form with a self-addressed stamped envelope in which you can return it to us. After we receive the consent form, we will contact you and arrange a time for an interview that is convenient for both of us. You will have the right to end the interview at any time if you start and then think that you might not want to finish the interview. If you complete the interview, you will be given a $25 gift card of your choice to either Starbucks or

Chipotle.

We appreciate your willingness to talk with us and are excited to hear what you have to teach us about your experience. Thank you for considering this opportunity to help the field of healthcare.

Barbara Couden Hernandez, Ph.D., LMFT, RN
bhernandez@llu.edu (909) 558-4730)

Lindsey Lawson, M.S. MFT, RN
lalawson@llu.edu (206-769-7419)

Carmen Knudson-Martin, Ph.D., LMFT
cknudsonmartin@llu.edu

INFORMED CONSENT: LLU

CURRENT ISSUES IN HEALTHCARE: PROVIDING FAMILY-CENTERED CARE AND EXPLORING ILLNESS NARRATIVES

(Please write your initials and the date at the bottom of each page)

Purpose and Procedures

You have been invited to participate in a study entitled "Current issues in healthcare: Providing family-centered care and exploring illness narratives."

The researchers are interested in learning about the challenges that healthcare providers face in their work, and some of their personal experience with illness. This study is being conducted by Dr. Barbara Couden Hernandez, Ms. Lindsey Lawson, and Dr. Carmen Knudson-Martin of Loma Linda University, Department of Counseling and Family Science, in the hope of making a significant contribution to our understanding and appreciation of the varied experiences of healthcare providers.

If you would like to take part in the study, you will be asked to participate in either an in-person or telephone interview with Dr. Hernandez or Ms. Lawson that will last between 60 – 90 minutes. Once the investigators receive your signed consent, you will be contacted by telephone to arrange a mutually acceptable time for the interview.

Your consent is required to record your responses during the interview. The conversation will be tape recorded and transcribed into a written document. The tapes will then be destroyed. All references to names, places, people, and in some cases, other occupations, will be changed or removed in order to decrease the likelihood that you could be identified based on your comments. Your interview will be added to a group of other interviews and analyzed collectively. Study findings will be used for professional training and future scholarly publications.

Risks

Although it is unlikely, the participant in the study may experience feelings of sadness or frustration during or after the interview due to discussion of personal experiences and challenges.

Initials _____ Date _____

Benefits

Nursing students, medical students, and medical family therapy students are offered a gift

card in appreciation of their participation. It is anticipated that participation in the study will help mental health professionals, nurses, and physicians to understand previously ignored experiences and challenges which healthcare providers often face. You might find it interesting and helpful to you to talk to a nonjudgmental interviewer about your private experiences. You may experience a sense of well-being in the knowledge that your participation will provide the basis for the creation of effective interventions and programs that include best practice models for healthcare and patient education.

Participants Rights

Your participation is completely voluntary. Should you decline to be interviewed, even after you have started to participate in the interview, there are no negative consequences and no ill will on the part of the investigators.

Confidentiality

The investigators <u>will not tell anyone</u> outside of the research team that you have participated in this study. Additionally, all personal information you share during your participation in the study will be held in strict confidence. Identifying material such as names, places, or anything that will allow people to know of your identity will not used in presentations or publications of study results. The tape transcriptions and all materials associated with this study will be stored in a locked file cabinet at Loma Linda University, Department of Counseling and Family Science.

In the unlikely event that you reveal unethical healthcare practices which are endangering patients' lives, the researchers will take steps to maintain patients' safety which may include discussion with school of school faculty or hospital employers.

Costs

There is no cost to you for participating in the study.

Reimbursement

Reimbursement for participation is a gift card given to you at the time of your participation.

Impartial Third Party Contact

If you wish to contact an impartial third party not associated with this study regarding any question or complaint you may have about the study, you may contact the Office of Patient Relations, Loma Linda Medical Center, Loma Linda, CA 92354, phone (909)558-4647 for information and assistance.

Initials _____ Date _____

Counseling Resources

       Behavioral Health Institute
       1686 Barton Road
       Redlands CA 92318
       909-558-9552

       Rhonda Thompson
       550 Orange Street Suite East
       Redlands CA 92374
       909-793-2701

       Patty Roth
       420 Brookside Ave.
       Redlands CA 92373
       909-363-1001
       …………………………………………………

Informed Consent Statement

I have read the contents of the consent form. I hereby give voluntary consent to be interviewed. Signing this consent document does not waive my rights nor does it release the investigators or institution from their responsibilities. I may call Dr. Barbara Hernandez, at (909) 558-4000 ext. 47041 or Ms. Lindsey Lawson at (206) 769-7419 if I have additional questions or concerns.

The interviewer(s) will review this consent with you at the time of the interview and will answer any questions you may have about your participation. If, after you sign this consent and discuss the study with Dr. Hernandez, Ms. Lawson, or Dr. Knudson-Martin you choose not to participate, you have the right to withdraw from the study at any time.

_____
Print your name here

_____ _____ _____
Sign your name here   Date

Initials _____ Date _____

Please list a telephone number at which the researcher may call you to arrange a convenient time for your interview. If there is a time of day that you prefer to be called, please indicate this as well.

Phone: _____

Times: _____

If you would like a copy of this consent form mailed to you, please provide your address here:

_____

_____

_____

_____

I have reviewed the contents of the consent form with the person signing above. I have explained potential risks and benefits of the study.

_____   _____   _____
Signature of Investigator   Phone Number   Date

INFORMED CONSENT: ECU, SPU

CURRENT ISSUES IN HEALTHCARE: PROVIDING FAMILY-CENTERED CARE AND EXPLORING ILLNESS NARRATIVES

(Please write your initials and the date at the bottom of each page)

Purpose and Procedures

You have been invited to participate in a study entitled "Current issues in healthcare: Providing family-centered care and exploring illness narratives."

The researchers are interested in learning about the challenges that healthcare providers face in their work, and some of their personal experience with illness. This study is being conducted by Dr. Barbara Couden Hernandez, Ms. Lindsey Lawson, and Dr. Carmen Knudson-Martin of Loma Linda University, Department of Counseling and Family Science, in the hope of making a significant contribution to our understanding and appreciation of the varied experiences of healthcare providers.

If you would like to take part in the study, you will be asked to participate in either a telephone or Skype interview with Dr. Hernandez or Ms. Lawson that will last between 60 – 90 minutes. Once the investigators receive your signed consent, you will be contacted by telephone to arrange a mutually acceptable time for the interview.

Your consent is required to record your responses during the interview. The conversation will be tape recorded and transcribed into a written document. The tapes will then be destroyed. All references to names, places, people, and in some cases, other occupations, will be changed or removed in order to decrease the likelihood that you could be identified based on your comments. Your interview will be added to a group of other interviews and analyzed collectively. Study findings will be used for professional training, development of innovative medical school and other healthcare training curricula, and future scholarly publications. Your faculty will not be told whether you participate or not, and the information you share with us will not be shared with them.

Risks
Although it is unlikely, the participant in the study may experience feelings of sadness or frustration during or after the interview due to discussion of personal experiences and challenges.

Initials _____ Date _____

Benefits
Participants are offered a gift card in appreciation of their participation. It is anticipated

that participation in the study will help mental health professionals, nurses, and physicians to understand previously ignored experiences and challenges which healthcare providers often face. You might find it interesting and helpful to you to talk to a nonjudgmental interviewer about your private experiences. You may experience a sense of well-being in the knowledge that your participation will provide the basis for the creation of effective interventions and programs that include best practice models for healthcare and patient education.

Participants Rights
Your participation is completely voluntary. Should you decline to be interviewed, even after you have started to participate in the interview, there are no negative consequences and no ill will on the part of the investigators.

Confidentiality
The investigators will not tell anyone outside of the research team that you have participated in this study. Additionally, all personal information you share during your participation in the study will be held in strict confidence. Identifying material such as names, places, or anything that will allow people to know of your identity will not used in presentations or publications of study results. The tape transcriptions and all materials associated with this study will be stored in a locked file cabinet at Loma Linda University, Office of the Director of Physician Vitality.

In the unlikely event that you reveal unethical healthcare practices which are endangering patients' lives, the researchers will take steps to maintain patients' safety which may include discussion with faculty or hospital employers.

Costs
There is no cost to you for participating in the study.

Reimbursement
Reimbursement for participation is a gift card given which will be mailed to you following the interview.

Impartial Third Party Contact
If you wish to contact an impartial third party not associated with this study regarding any question or complaint you may have about the study, you may contact the Office of Patient Relations, Loma Linda Medical Center, Loma Linda, CA 92354, phone (909) 558-4647 for information and assistance.

Initials _____ Date _____

Counseling Resources (SPU)

    SPU Counseling & Student Development Center
    Watson Hall
    (206) 281-2657

Eric Gomez, MS, LMFT, MHP
444 NE Ravenna Blvd., Ste 301
Seattle, WA 98115
(206) 852-7363

3. Kara Bazzi, MS, LMFT
1107 NE 45th St., Ste 410
Seattle, WA 98105
(206) 999-1227

Counseling Resources (ECU)

ECU Counseling & Student Development Center
Umstead Building
(252) 328-6661

David Knappenberger, MS, LMFT
620-A Lynndale Court
Greenville, NC 27858
(910) 756-7533

Maggie Yankov, MS, LMFT
620-A Lynndale Court
Greenville, NC 27858
(252) 557-9954
……………………………………………………

Informed Consent Statement
I have read the contents of the consent form. I hereby give voluntary consent to be
interviewed. Signing this consent document does not waive my rights nor does it release
the investigators or institution from their responsibilities. I may call Dr. Barbara
Hernandez, at (909) 558-4000 ext. 47041 or Ms. Lindsey Lawson at (206) 769-7419 if I
have additional questions or concerns.

The interviewer(s) will review this consent with you at the time of the interview and will
answer any questions you may have about your participation. If, after you sign this
consent and discuss the study with Dr. Hernandez, Ms. Lawson, or Dr. Knudson-Martin
you choose not to participate, you have the right to withdraw from the study at any time.

_____

Print your name here

_____

Sign your name here   Date

Initials _____ Date _____

Please list a telephone number at which the researcher may call you to arrange a convenient time for your interview. If there is a time of day that you prefer to be called, please indicate this as well.

Phone: _____

Times: _____

If you would like a copy of this consent form mailed to you, please provide your address here:

_____

_____

_____

_____

I have reviewed the contents of the consent form with the person signing above. I have explained potential risks and benefits of the study.

_____   _____   ____
Signature of Investigator   Phone Number   Date

TELEPHONE SCRIPT

Hello,

Thank you for indicating your interest to be involved in our study entitled, "Current issues in healthcare: Providing family-centered care and exploring illness narratives." This is an interview-based research project that we hope will help us understand better some of the challenges that nurses face in their work, and some of their personal experience with illness.

Many of the important facts about the study were given on the email you were sent. Do you have any questions about any of the information or anything else that pertains to this study?

(May refer to this list of facts if potential participant requests more information): Men and women in the following four categories are needed for this study: nursing students, medical students, medical family therapy students, and practicing physicians.

The researchers will ask questions about your personal, educational, and professional background. Once you agree to speak with the researcher you will have the right to withdraw from the interview at any time if you choose.

The interviews will last between 60 – 90 minutes, depending on how much the participants decide to speak with the researchers.

The names of individuals who choose to participate will remain confidential and will not be divulged to anyone outside of the research team.

The interview will be tape-recorded and written down. Anything that might identify the interviewee will be removed or changed (names, places, ages, etc.) so that no one will be able to recognize anyone who has shared their story.

Participants will be given a gift card for their participation in the study.

Participation is voluntary and hospital staff, employers, and faculty will not know whether you choose to be interviewed or not unless you tell them.

We will send you a consent form that you can sign, scan, and return via email, should you accept the invitation to participate.

We will call you at the number designated on your consent form in order to schedule an interview time that is convenient.

This research will be used to help medical family therapists, nurses, physicians, and nursing educators to understand the experience and needs of healthcare providers more fully.

I have an Informed Consent document that I will ask you to review and sign when we meet (Southern California participants only), and it details all of the privacy and confidentiality information for this project. We also have a short Demographic Questionnaire that we will ask you to fill out, in which you can tell us very briefly some facts about you: how many years you have worked, your age, race, religion, and such. This will also be used in our research analysis and give us a context for the information you share with us.

Do you have any other questions?

Are you interested in being a part of this research project?

Have I answered your questions adequately about confidentiality and how we will use the information that you provide for us?

When might be a convenient time to meet with you? We need to allow about 90 minutes for this interview.

Okay, we will meet at … o'clock on …. at…….

If you have any questions in the meantime, or if we need to change the time or location for our meeting, please call me at _____ so we can make the changes needed.

Do you have any other questions?

Okay. Thank you so much, and I will see you at …. o'clock on ….at……

Goodbye.

APPENDIX I

DEMOGRAPHIC QUESTIONNAIRE

Please respond to all items that apply to you:

Age _____   Race _____

Religion _____

Marital status _____

Number of children _____

Nursing Students

Nursing degree (A.S., B.S., M.S., D.N.S., Ph.D., Dip, etc.) _____

College/university where degree obtained _____

Years or months as an RN _____

Current type of nursing (med-surg, ICU, etc.)_____

How many years in your current position? _____

Previous type of nursing experience_____

_____

Medical Students

Year in your program: _____

Clinical rotations completed: _____

_____

Medical Family Therapists

Degree program (M.S., M.A., Ph.D., DMFT, PsyD, etc.) _____

Clinical practicum/internship experience: _____

_____