THE CLINICAL DECISION SUPPORT LIAISON:
A NOVEL MEANS FOR SUPPORT IN ACUTE CARE

BY

LAURA A. SCOTT

A Thesis Submitted to the Graduate Faculty of

WAKE FOREST UNIVERSITY GRADUATE SCHOOL OF ARTS AND SCIENCES

in Partial Fulfillment of the Requirements

for the Degree of

MASTER OF ARTS

Bioethics

May 2017

Winston Salem, North Carolina

Approved By:

Nancy M.P. King, JD, Advisor

John C. Moskop, PhD, Chair

Deborah Love, JD

ACKNOWLEDGMENTS

First, I would like to thank the faculty and staff of the Bioethics Graduate Program for the encouragement and education provided throughout my time as a student. In particular, I would like to thank Nancy King for her guidance throughout the writing of this thesis and for her encouragement to explore more deeply the potential bioethics adds to my practice.

Second, I'd like to thank Deb Love for the opportunity to perform this practicum as well as her ongoing faith and encouragement. I would also like to thank the staff at Novant Health with whom I worked to complete this pilot, including Melanie Kelly, Adam Koontz, Sara Bridges, and the staff and providers of the Neuro ICU and Oncology floor.

Finally, I would like to thank my husband, Andy, and two daughters, Josie and Ellie. Without their patience, love, and ongoing support, I could not have completed my graduate degree(s). You all worked hard for this too, and I love you.

TABLE OF CONTENTS

LIST OF ABBREVIATIONS

AMA   American Medical Association

CDSL   Clinical Decision Support Liaison

ICUN   Intensive Care Unit - Neurology

IOM   Institute of Medicine

MSAP   Munchausen's syndrome by proxy

NASW   National Association of Social Work

NH   Novant Health

WHO   World Health Organization

ABSTRACT

The health care system, along with other service industries, has recently
sought to serve patients through models of person-centered care. Bolstered by
ideals of respect for autonomy and individual values, medical professionals seek to
provide medical care that supports the well-being of patients beyond physiology
alone. However, in the acute hospital setting there exist numerous barriers that
make this goal difficult. Physicians and staff are faced with ethical dilemmas daily
while encountering patients faced with high stress situations, critical decision-
making, and planning for the future in the context of serious illness. Providers of
medical care are often unable to help resolve these situations due to their competing
obligations.

This practicum-based thesis is based on my experience piloting the new role
of Clinical Decision Support Liaison at a Novant Health tertiary care center. This role
intended to serve patient needs through increased conversations about goals and
improved communication between physicians and patients. During this practicum I
discovered the palliative nature of exploring patient values, assisting with decision-
making, and offering support to patients in the inpatient setting; each of these
measures brought comfort to patients. While engaging in ethical evaluation, I also
provided invaluable support to patients through communication skills and
mediation. My practicum experience suggests that in seeking person-centered care,
hospitals must focus on both the physiological and the psychosocial sources of well-
being in patients.

The following chapters include information regarding the intent and development of the new role, the impact of the role as illustrated by three narratives of my encounters with patients and staff, and my reflections and recommendations for implementation of this role in the future.

INTRODUCTION

Proactive Palliative Care Consultation: A Social Work Perspective

Palliative care has become significantly more embedded in the health care

system over the last decade. It is more broadly valued as a necessary discipline for

patients living with serious illness or at the end of life, offering comfort care in

addition to medical interventions. Even in this more welcoming climate, however,

there still remain barriers to its use for some patients. Palliative care is a discipline

that requires a medical system to discern the patient's goals and wishes rather than

treating only the body's ailments; time constraints, discomfort, and a

misunderstanding of the purpose of palliative care can all prevent the treating

medical providers[1] from introducing the option of palliative care to patients whose

deaths may not be imminent. From this, gaps arise in both the identification of need

for palliative services and subsequently the provision of palliative services. In order

to close these gaps, there is a need for another clinician who can gather information

about the lives and treatment goals of patients, educate patients about advance care

planning and palliative care options, and connect the treatment teams with that

information. This thesis explores filling that gap through a proactive role in

palliative care and is based on a practicum in which I piloted a new position, the

Clinical Decision Support Liaison (CDSL) at a Novant Health (NH) tertiary care

center. I begin this exploration with some definitions of concepts surrounding

palliative care and the role of social work within palliative care.

---

[1] For the purpose of this thesis, I will refer to physicians, physician assistants, and nurse practitioners as "providers."

Relief of Suffering as a Medical Moral Duty

First, very broadly, there exist societal expectations of the health care community. Pellegrino and Thomasma (1993) defined physicians as "the moral center of health care," and considered them obligated to at least attempt to relieve the suffering of their patients (p. 37). Further, in its code of ethics the American Medical Association (AMA) defines the practice of medicine as "fundamentally a moral activity that arises from the imperative to care for patients and to alleviate suffering" (AMA, 2016, p. 1). Health care professionals embrace a central obligation to relieve suffering. In a simplistic example, when patients present to a physician's office with pain from symptoms of a minor infection, they anticipate that the physician will provide a diagnosis and treatment, subsequently relieving the pain. Cassell (2004) stated that the imperative of physicians to relieve suffering is founded in a system of trust. He explained that doctors "are people who, because of their special knowledge, are empowered to act by virtue of the trust given by patients, and who thereby acquire responsibility" to act (p. 72). Similarly, Pellegrino and Thomasma (1993) stated that patients are forced into the role of vulnerability by the "predicament of illness;" because they are ill and need relief, they must trust the physician, creating an imbalance of power (p. 35). This imbalance of power then exacerbates the patient's vulnerability to suffering; because the physician, due to professional obligations, should relieve suffering, this imbalance of power imbues the physician with a special responsibility. The medical provider is a knowledgeable source of information and healing, and must use his/her knowledge to remedy patients' suffering.

Palliative Care: Reframing Relief of Suffering

While physicians are all trained to relieve suffering through curative medical treatments, palliative care broadens the concept of suffering to include existential variables. The World Health Organization (WHO) defines palliative care as improving "the quality of life of patients and their families...through the prevention and relief of suffering...and the treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2014). There exist two primary goals of palliative care in this definition that are essential to this brief discussion.

First, palliative care aims to improve the quality of life for patients and their families through treatment of simultaneous forms of suffering. Alleviating the multiple aspects of suffering includes symptom management to reduce physiological pain, support to relieve psychosocial stressors, and support for spiritual guidance. The goal to relieve suffering speaks to the very origins of palliative care in the 1960's when Dame Cicely Saunders noticed that the dying individual was fundamentally abandoned by medical practitioners once treatment became futile (Thoresen, 2003). She recognized and wanted to relieve the "total pain" in the dying experience, wherein the patient suffers from a "complex of physical, emotional, social, and spiritual elements" (Saunders, 1996, p. 1600). In palliative care practice, the medical team seeks to remove the harms that come with serious illness and the process of dying, including fear, pain, and generalized suffering. This practice of palliative care requires medical practice to be virtuous; the medical providers must be able to recognize suffering and act with compassion for vulnerable patients.

A second goal identified in palliative care is the importance of acknowledging autonomy through assessment of individual needs. This goal is entwined with the previous one because in order to appropriately relieve the existential suffering, or "total pain" that comes with serious illness, practitioners must first be able to identify the individual experiences of patients, from which arise the unique preferences made by autonomous individuals (Saunders, 1996, p. 1600). Beauchamp and Childress (2009) outline the requirements for autonomy, which is validated when individuals are able to make choices in healthcare without the constraints of undue influence or lack of understanding. Just as patients hope to have autonomy in decisions in medical matters from which they will recover, they also hope to remain autonomous in making choices about treatment in the midst of serious illness and at the end of life. Saunders (1996) observed that dying was as individual as "the life that preceded it" (p. 1600). Palliative care identifies and serves the individual needs of patients through a multidisciplinary approach that recognizes and respects the humanity in every person, thus supporting their right to autonomous choice.

Seeking "Person-Centered" Healthcare

Related to palliative care is the concept of "person-centered" healthcare. Because improving comfort through serving individual needs of patients is central to palliative care, and because person-centered care generally holds that the individual needs of patients are central to excellent health care delivery, it follows that these two concepts are interrelated. The development and widespread understanding of person-centered care is still evolving in the literature, however.

In 2001, the Institute of Medicine (IOM) published a report outlining quality

improvements needed in healthcare, and defined patient-centered care as

"providing care that is respectful of and responsive to individual patient

preferences, needs, and values, and ensuring that patient values guide all clinical

decisions" (p. 3). This definition laid groundwork for consideration of a medical

encounter that was not limited to physiology, but also considered the cultural and

value-based needs of patients. At the same time, this initial definition of patient-

centered care did not satisfy others in healthcare, in particular because it was tied to

other goals of efficiency and improved delivery of healthcare in the IOM report.

Hoping to redefine patient-centered care as a goal in and of itself, Berwick (2009)

proposed another definition: "the experience (to the extent the informed, individual

patient desires it) of transparency, individualization, recognition, respect, dignity,

and choice in all matters, without exception, related to one's person, circumstances,

and relationships in health care" (p. w560). Both of these definitions attempted to

reorient medicine so that the patient was the central focus in the healthcare

encounter; however, in the implementation of this ideal, it became clear that

another redefinition might be necessary.

Starfield (2011) points out that in many articles, measures of improvements

in patient-centered care are tied to the communication skills of physicians; if

physicians implement improved communication strategies, patients are more

informed about their care, are possibly more agreeable to medical interventions,

and are generally more satisfied with their care. Notably, this orients the goal of

patient-centered care back toward outcomes of healthcare delivery, rather than

keeping the patient's personal development at the center. Starfield (2011) further

argues that a person-centered healthcare delivery system must have at its center a

longitudinal understanding of patients' needs over time; only within that deeper

understanding of patients' lives can medical providers make appropriate

recommendations for individual patients. Although they are similar concepts, a

patient-centered approach focuses more narrowly on the patient within the medical

encounter; the person-centered approach attempts to also include consideration of

the multiple dimensions of the life of the person beyond the medical encounter.

Eckman et al. (2011) offer the following definition of person-centered care:

> A person-centered approach to care sets the person's views about his/her
> life situation and condition irrefutably and always at the center of care. The
> patient narrative is the sick person's personal account of his/her illness,
> symptoms, and their impact on her/his life. It captures the person's suffering
> in an everyday context, in contrast to medical narratives that reflect the
> process of diagnosing and treating the disease. (p. 3)

Of course, this is an idealistic form of healthcare delivery. Upon consideration, one

can easily predict that physicians and administrators alike will encounter difficulty

imagining how to access this deeper patient narrative; physicians and nurses are

already pressed for time in the medical system. At the same time that the ideals of

patient-centered or person-centered care are being promoted, standards of

efficiency have restricted the opportunities for physicians to establish rapport with

patients and thus have reduced many patient interfaces to little more than clinical

encounters.

Aligning With Social Work

It is notable that the person-centered approach is very much aligned with the

values embraced by social work. In its code of ethics, the National Association of

Social Work (NASW) states that the "mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable…" (NASW, 2008, preamble). Furthermore, the standards of social work require social workers not only to consider the dignity and worth of patients to be paramount, but also to be aware of the vulnerability of patients in varying contexts. Individuals are comprised not only of their biology, but also the sum of their experiences in life. Systems of oppression and privilege at multiple levels influence individual experiences, from family dynamics to policy-level decisions that affect interactions with public services. From these experiential processes emerge individuals with complex stories that influence self-concept, behaviors, and interactions with others and the larger society. Considering their commitment to persons as complex, vulnerable, and valuable, social workers on the medical team are in a unique position to gather the narratives of patients, and thus help create a person-centered framework in the medical system.

Closely related, social workers are frequently utilized as part of palliative care teams. The struggle of serious or terminal illness brings with it myriad types of suffering, including physical, spiritual, and psychosocial. Social workers, given their training and focus on the worth of individuals, are an integral support. As noted by Otis-Green et al. (2014), social workers on the palliative care team are called on to assist patients in the physical, psychological, social, and spiritual dimensions of well-being. On the specialized palliative team, the social worker will offer counseling for both the patient and the family unit; as people experience the difficulty of illness, the

social worker is present to assist with grief related to the decline of the patient and other related emotional stressors. Outside of the specialized palliative team, a social worker can also provide emotional and psychological support to patients who are struggling with decision-making or living with chronic or serious illness. Each role is central to improving patient-centered care, and each serves to improve the comfort of patients through social and psychological support. The dynamic approach of social work prepares its professionals to alleviate suffering of individuals in many contexts.

Structure of the Thesis

With these concepts in mind, this thesis relates my experience in the role of a CDSL. I approached this role with a background both in Bioethics and Social Work, and thus my interactions within the hospital system were influenced by both of these disciplines. Furthermore, I believe my education in both of these disciplines improved my efficacy at this role in a unique way.

In the first chapter, I present the context, development, and intent of the role of CDSL, as well as the structure of my experience in the hospital. In the following three chapters, I present and analyze three patient narratives that illustrated the significant and dynamic potential this role has for hospital systems. I would like to note that because I am not a medical provider, my narratives do not contain detailed medical terminology; instead they are rich with psychosocial and ethical dilemmas. In the fifth and final chapter, I conclude this thesis with reflections on my experience of this role as a type of proactive palliative care, reflections on the usefulness of

combined knowledge of social work and bioethics, and a summary of the outcomes

of the role and the potential for this role to advance the medical system.

CHAPTER 1 - THE PRACTICUM

My intention for a thesis topic had always been exploring the meaning and

feasibility of moving palliative care "upstream" in the medical encounter. While I

imagined that I would write in a traditional thesis format, an opportunity arose to

explore these ideas through a practicum when Deborah Love, Senior Director for

Bioethics, Spiritual Care and Healing Arts for NH, approached me in the spring of

2016. She explained that her team wanted to perform a pilot of a new role in acute

settings of a local hospital; this role would assist with support for families, help with

decision-making and identification of patient goals, and assist medical teams with

identifying other useful in-hospital resources such as palliative care. Because this

role intended to promote these conversations among medical teams outside of

palliative care, and because it was aligned with the ideals of person-centered care, I

agreed to participate in the pilot and use this experience as a means to explore

aspects of delivering some of palliative care upstream. In this chapter, I explain the

context, development, implementation, and outcomes of this practicum.

The Setting

The practicum would take place within a NH tertiary care center. Almost

immediately, I realized that this would be an excellent setting in which to investigate

the potential for proactive palliative care; NH has a central mission to provide

"remarkable" patient experiences, which speaks to a goal for person-centered

healthcare. Any member of a community in which NH has a presence has the

opportunity to notice this marketing campaign; both their facilities and local

advertisements make it clear that they are seeking to bring the patient story to the forefront of medical encounters.

Within NH, the pilot originated under the umbrella of its Choices and Champions®, the aim of which is to transform care across the healthcare continuum leading to end of life, by knowing and honoring patients' wishes. NH began this program in order to actively work toward more person-centered care at the end of life and during the experience of serious illness. The guiding principles of Choices and Champions® are as follows:

> 1. Focus on patient empowerment rather than death or dying.
> 2. Consider the individual's goals for his or her life when making medical recommendations.
> 3. Emphasize the importance of conversations rather than legal healthcare directives.
> 4. Engage patients and their loved ones early in the care continuum rather than waiting until the end of life to address end-of-life issues.
>
> (NH Choices and Champions® Steering Committee, revised 9/30/16, Materials in possession of author)

These guiding principles aim to inform healthcare at NH through the implementation of specific goals such as continuing to advance the communication abilities of providers at all levels in the healthcare system, systematically helping patients identify a healthcare agent, and encouraging conversations that help patients identify their life goals and their treatment goals. As we consider the focus of Choices and Champions®, its name becomes clarified. Patients are encouraged to identify their "Champions," or the person who can serve as the patient's health care

decision-maker if necessary and their "Choices," or their goals for treatment. By working toward making these conversations an everyday aspect of healthcare delivery, NH is already promoting proactive measures to increase the comfort and autonomy of individual patients at the end of life and also increase the likelihood that patients' families and physicians will understand and honor the decisions made. Because these measures are in place, a NH facility was ideal for this practicum; it was already incubating the questions I seek to explore.

The Concept

While working to resolve the issues it sought to address, the implementation of Choices and Champions® unearthed more subtle problems acting as obstacles to the improvement of health care at the end of life. Among others, these obstacles included time constraints, communication skills, comfort level of providers in difficult conversations, and a lack of understanding about the purpose and value of palliative care. The Choices and Champions® team identified a need for a neutral team member to help guide patient discussions regarding health and life goals and assist providers with identification of possible resources.

Before the pilot began, I met with both Deborah Love and Melanie Kelly, Corporate Director of Palliative Care for NH, multiple times to explore the concept of the pilot, including its defined role and title, and measures that would indicate success in implementation.

In defining the concept, we discussed the difficulties experienced by patients with serious illness. Drawing from much of our own personal experience, and without judging the individual intent of each provider, we noted how easily the

narrative of the patient is lost as more sub-specialists of medicine are consulted in the care of a patient. As each specialist focuses on the bodily system in which he/she is expert, too often the global experience and effect of medical interventions is forgotten. Without that larger systemic view, the patient's life, interests, and goals are frequently overlooked. The intent of this role was to elicit the patient's hopes, fears, life goals, and values and reflect these in the medical record so that the medical team can better serve their patient as a whole person. With that knowledge in hand, providers can better align treatment options and recommendations with patient values and preferences.

Furthermore, as we considered the experience of patients in acute care settings, we realized that the patients are frequently faced with multiple complex decisions related to their medical care. Without identification and discussion of personal goals and acknowledgement of their importance in medical decision-making, patients may not be prepared to make quick decisions aligned with those goals. In addition to discussion related to these goals, we hoped to prepare patients for decisions by creating prognostic awareness and encouraging conversations with loved ones. With each of these measures in place, eventual surrogate decision makers are better equipped to exercise substituted judgments on behalf of the patients rather than interjecting their own personal values and preferences. Thus, the second conceptual ideal of this role was to help empower patients' wishes through increased understanding as well as identification and affirmation of patient goals in order to assist them with complex medical decision-making.

Although the intentions of the role seemed clear, the actual duties of the role remained amorphous. Because each patient and family bring with them an individual culture and experience, and because we wanted this role to be without a specific agenda beyond support and creating a stronger connection between the clinical and personal encounter, we had difficulty specifically defining what the duties of the role would entail. Among other supportive duties, the role could include assistance with medical decision-making, psychosocial support, mediating conflicts between patients and providers, and completion of advance directives when possible. The multi-faceted nature of the pilot led to numerous discussions about the role title. After considering multiple ideas, we decided on "Clinical Decision Support Liaison," which reflected the ability of the role to fill numerous duties to support the patient experience in the clinical encounter.

The reason for this pilot was to assess the effectiveness of this role in furthering the Choices and Champions® goal to know and honor patients' wishes across the care continuum. It was a challenge to determine how to measure success in this pilot both due to its short time period and because its measures were qualitative, subjective, and experiential. The pilot would run for six weeks, and in that period, it was not possible to extract significant quantitative data for two reasons. First, we did not believe that I would encounter enough patients to have a significant data set. Second, in that time period we did not anticipate that we would reach long-term measures such as reduced inpatient stays, reduced readmissions, or staff retention. Furthermore, because the goal of the role is steeped in subjective data such as increased patient-focused care and patient satisfaction, adequate

measurement tools were unclear. In the end, it was determined that the role could be defended on the number of referrals I received from team members and statements of need and gratitude from patients and team members. Furthermore, we decided that we would rely on compelling narratives to demonstrate need for this position.

The Implementation

Prior to implementation it was determined that the pilot would run for a six-week period with 180 contact hours during the summer. In order to examine its efficacy in the acute setting but still retain some diversity in illness typology, I would be working primarily in the Intensive Care Unit-Neurology (ICUN) and secondarily in the Oncology Unit.

The success of the pilot relied significantly on the number of referrals I received from staff and providers. To that end, it was imperative that I encourage referrals to my services by educating my colleagues about the purpose of this role and establishing a consistent presence on the units. I implemented the education by introducing myself to physicians, nurses, and other team members on a daily basis; each time I saw a new face, I made an effort to introduce myself and my role, encouraging them to consider my services if they encountered a patient or family who could use assistance. In most cases, this explanation was met with excitement – it was immediately apparent that medical staff thought this role was necessary and missing for patients not yet at the end of life in the acute care setting. In order to establish my presence, I committed to attending interdisciplinary rounds on both the ICUN and the Oncology Unit with the intention of gathering referrals in these

meetings. I discovered that attending provider rounds each morning in the ICUN, along with checking in with nurses, was more fruitful in obtaining referrals. In the Oncology Unit, the interdisciplinary rounds were a source of referrals, but I also relied on contact with a provider on the unit for additional referrals.

There were notable differences in serving the patients on the ICUN and the Oncology Unit. Because the ICUN was my primary focus, I built relationships with the staff more quickly; it was through building that relationship that the staff understood my role and made regular referrals to me. Additionally, however, the different disease processes created different needs among the patient populations. In the ICUN, I encountered patients who had usually experienced sudden and devastating neurologic events such as strokes, intracranial hemorrhages, or diagnoses of brain cancers. These patients and families frequently appeared in shock; they were thrust into a new health situation and were receiving significant amounts of medical information that often required thoughtful and expedient decision-making. In the Oncology Unit, I primarily received referrals from a mid-level provider on the unit. The referrals on this unit reflected the long-term disease process of cancer. The patients she referred varied with regard to the stage of their illness. Some were long past the surprise of a cancer diagnosis and were at a point of making decisions whether to continue treatment; other patients had just begun their treatment journey and were in need of support while they received treatment. Because the patients with cancer I encountered were experiencing a much longer-term disease process, they had built relationships with staff and had more time to contemplate their needs and hopes for the future. Both patient populations were in

need of support and assistance with decision-making, but the timeline of illness created differences in the urgency of the process.

In addition to interacting with unit staff and intervening with specific patients on these two units, we also hoped to get a sense of the need for this position in other areas of the hospital. To that end, I was able to attend a weekly case management meeting that reviewed the most complex cases, or patients who had been in the hospital for an extended period of time, in order to assess the scope of need in a larger subset of patients.

As noted previously, each patient and family I met presented with different needs, but each benefited from the opportunity to talk about their worries, goals, and values. Many families simply needed additional psychosocial support; for these families I offered empathy and the time to sit, listen to, and acknowledge their emotional suffering during their acute experience of illness. Other times practitioners were concerned that families and/or patients did not have an adequate understanding of their illness and options; for these families I provided support and also assessed their understanding of the illness. Notably, many times these patients articulated adequate understanding, and also communicated goals that differed from the medical course providers anticipated.

The Outcome

At the end of the six-week period, I had encountered 50 patients. Most were brief meetings to provide support for families, but approximately 30% of my encounters with patients and families resulted in significant relationships. Several of these relationships developed quickly due to the acute nature of the medical issues

at hand while others developed over the course of a lengthy hospital stay. Each of these relationships, however, was meaningful and resulted in objective benefits to patients, their families, and the hospital system.

The pilot role contributed to a positive outcome for most of the patients and families encountered, but the limited scope of the trial offered minimal quantitative data on the long-range outcomes predicted. However, it cannot be said that this role was without benefits. Measures of success included positive feedback from patients, families, staff, and physicians, and potential reduction in healthcare costs due to reduced days in critical care units. Each of these outcomes is explored further in Chapter 5, but some of the positive measures are illustrated in the narratives and analysis of the following chapters.

CHAPTER 2 – MS. C

Narrative

One of the most common consults I encountered during this practicum

entailed providing support for patients and families during times of difficult medical

decision-making. Frequently, a provider felt that a patient was "stuck" and needed

assistance with identifying goals of care. A significant lesson learned from these

encounters is the need to expand advance care planning beyond the scope of

advance directives. Helping patients identify their life goals and then further

communicating those goals to providers proved an invaluable resource. Often a

simple intervention created significant shifts in a patient's course, resulting in

noticeable increases in patient and family comfort.

My first experience with this transformative shift occurred on the Oncology

floor. A provider approached me to offer counseling to a patient ("Ms. C") who had

experienced multiple recurrent admissions in a short time. The provider expressed

concern regarding the situation for two reasons. First, she was unsure that Ms. C

understood her diagnosis and prognosis, and wondered if this was the reason she

continued to seek aggressive treatment rather than exploring comfort options.

Second, Ms. C had no insurance and, because she had recently moved to North

Carolina, was facing obstacles to qualifying for Medicaid; her insurance status raised

concerns about possible future financial issues. I agreed to visit to assess her

understanding of her illness and her goals of care.

Ms. C and her partner (Mr. D) were in the room, sitting quietly. They

welcomed me in, but seemed hesitant to talk as we ventured into difficult topics,

including whether they had discussed advance directives. When I asked this question, Ms. C bristled, telling me that so many people had asked that question that she was wondering if there was an urgency about her prognosis about which she was unaware. I assured her that it was simply that our staff believed advance directives to be important for everyone, and she calmed quickly. Fairly soon after that, Mr. D excused himself to go home and get cleaned up, and after he left, Ms. C opened up a bit more.

She explained that she was exhausted by her seemingly constant visits to the hospital. Her readmissions were due to the recurrence of dangerously low sodium levels; her cancer was causing these acute episodes. She expressed awareness that her condition was terminal but also expressed an understanding that treatment possibilities still existed and that she was not yet ready to stop trying.

She then shared that she and her partner had indeed recently moved to North Carolina from Kentucky and had few social supports in place. When I asked her about goals, it was apparent that she had been considering this question for some time. She openly and clearly stated that she wanted to get back to Kentucky to be closer to family. In her hometown lived her two daughters, a toddler granddaughter, and her mother. She had even researched the local cancer center and found a physician who specialized in her type of cancer. Her only impediment was figuring out how to get there; between her unstable sodium levels, recurrent admissions, and partner's obligations, she simply could not make the trip happen. I was astounded that she had not shared this with any of the providers or staff. When I asked why, she explained that they simply had not asked.

I documented this meeting very plainly in the record, indicating her social supports, her primary goal of getting home to Kentucky, and the research she had done regarding where to transfer her medical care.

When I checked Ms. C's medical record again two days later, I discovered that her oncologist had confirmed her goal and was now researching how to help her achieve it. The physician had already reached out to her physician colleague in Kentucky to see how to safely transfer Ms. C into his care. At this point, I visited Ms. C again, and she joyfully expressed that the team was working to see when she could get to Kentucky.

Ms. C then went to her home in North Carolina with the intent of getting things packed up prior to her next admission, but ended up in the hospital again fairly quickly. As her situation appeared to be increasingly urgent, she had her partner pack her things into her car. I visited once more, but since her needs were being met, I offered brief support. After that, I understand that the team was able to stabilize her sodium levels and discharge her quickly one morning; from that point she drove herself home to Kentucky and made it there.

Analysis

Conversations about treatment and life goals can be some of the most crucial interventions available to clinical caregivers when working with people living with serious illness or at the end of life. Each patient and family system brings with them a lifetime of unique experiences and relationships that shape who they are and their priorities. In order to provide true comfort to patients with serious illness, the medical team must be aware of these goals. This comfort comes in the form of

acknowledgment of these goals as well as at least attempting to allow those goals to shape treatment. While conversations about goals can be complex, possibly requiring guidance by providers, social workers, and/or chaplains, in the case of Ms. C, it was a simple intervention with a significantly positive outcome for the patient and her family.

In this case, I found it surprising that the medical team had not asked Ms. C about her goals even though numerous staff had asked about her advance directive status; her life goals appeared both simple and accessible in our conversation. It highlighted to me the need to reorient the meaning of advance care planning to move beyond the paperwork of advance directives. Although advance directives are crucial to ensuring that patient's wishes are followed at the end of life, the process of treatment up until their use may contain hopes, wishes, and fears that guide choices for medical intervention.

However, I also must acknowledge the constraints felt by providers and staff that probably inhibit their ability to discover goals of care for each patient. In their review of the literature, Slort et al. (2011) found multiple barriers that prevented conversation about difficult topics, including time constraints, patients' unwillingness to engage in the conversation, and providers' lack of personal commitment to supporting patients through difficult conversations. I think each of these were possible contributing factors to the lack of conversation in this case as well. First, and most important, the oncology floor in an acute hospital does not allow its staff ample time for lengthy conversations; it is common for both nurses and providers to be overwhelmed by their assignments. They are already stretched

thin for time, and it is hard for them to imagine being able to sit in a patient's room

to conduct a thoughtful conversation about goals of care without neglecting the

needs of other patients. Second, Ms. C was not the easiest person to engage.

Although she did not refuse the visit, Ms. C did not open up conversationally until

after Mr. D left the room. Without the luxury of time, it is doubtful that a staff

member or provider could take the time to discover the circumstance in which Ms. C

was willing to engage in this conversation. Third, although I believe the staff and

providers know the importance of these conversations, they do not all have the

training to begin and sustain these difficult conversations, which would probably

have an effect on their confidence and commitment.[2]

Although these limitations reduce the ability of staff and providers to

conduct these conversations, it is clear that the importance of these conversations

cannot be overlooked or minimized. Consider, as noted by Stone (2001), that the

patient, through his or her experiences and choices throughout life, is led into

decision making by "a very personal sense of what brings greatest meaning and

value and adds most to his or her quality of life" (p. 134). Simultaneously, patients

lose control over many life choices through medical decline and related hospital

stays. The hospital context can be bewildering to patients and their families; a

combined loss of control and a disrupted, uncomfortable existence do not lend the

hospital stay a sense of well-being beyond the physiological. As medicine aims for a

goal of achieving well-being for patients with incurable diseases, it must look

---

[2] Notably, NH is committed to improving the efficacy with which staff and providers conduct difficult conversations with patients; through its ''Mastering Conversations That Matter'' program, NH is already working toward system-wide improvements.

beyond the physiological to the spiritual and psychosocial. In order to address

human needs beyond the physiological, we must begin with implementation of

discussions regarding goals of care; without patient input received in those

conversations, work toward a more holistic sense of well-being is a fruitless

endeavor.

There are simple and vital components of effective discussions regarding

goals of care, including the act of asking, the time to listen, and the documentation of

the conversation in the medical record. Improvements in physician communication

and patient care have become a focus in medical education, and yet the barrier may

be as simple as having the courage and tools to ask patients about fears and goals.

To that end, articles by Dunlay and Strand (2016) and You et al. (2014) outline

specific methods to successfully begin the conversation and elucidate patient goals.

Common themes in these articles include assessing patient understanding of illness,

acknowledging the uncertainties underlying prognosis, discussing risks and benefits

of various options, and exploring patient values. Also, centrally important to any

conversation, the provider's ability to listen to the values and goals of patients is

fundamental to the success of conversations about goals. Multiple studies have

shown that effective and reflective listening skills on the part of providers increase

patient confidence and autonomy, strengthen the patient-provider relationship, and

decrease stress for patients (Jagosh et al., 2011; Pollak et al., 2011).

A final and crucial aspect to these conversations is their documentation in

the medical record because it "maximizes the likelihood that a patient's previously

expressed wishes will be successfully translated into actual care received" (You et

al., 2014, p. 430). I cannot be certain that Ms. C had not told anyone else about her hope to return to Kentucky to be near her family during her illness and decline; I am, however, fairly certain that I was the first to clearly elucidate this goal in the medical record. A phenomenon occurred after I mapped out Ms. C's and other patients' goals; after this documentation, multiple records echoed those goals, creating a sense of affirmation of goals and change in the team's focus. It was heartening to see the medical team orienting toward patient goals and gratifying to help patients regain a sense of control in their lives.

It should also be acknowledged that the hospital system must orient their electronic medical record in order to foster the creation and accessibility of notes that provide the patient narrative. Because the NH system promotes the use of advance care planning notes as well as the inclusion of patient narratives in the record, disbursement of this information to the team was made easier.

In this case, as well as numerous others during the course of the practicum, it was clear that the important conversation and the subsequent documentation in the medical record helped guide final outcomes for patients. Because the guiding principles for the outcomes were based on the patients' own values and hopes, I believe we can safely assume that the well-being of these patients was increased.

CHAPTER 3 - MRS. A & ANNA

Narrative

Some of the most meaningful encounters I experienced were in interactions

with the patients considered by the staff and providers to be the most difficult.

When patients do not easily acquiesce to the recommendations of providers, serving

their needs becomes complex and runs counter to the streamlined nature of the

current medical system. These encounters offered an extension of the palliative

model as it joins with ethics – I offered comfort for these families through

counseling, assistance with communication, and advocacy. I began the relationship

with one of my most difficult and rewarding patients soon after starting the

practicum.

In my second week, when I felt that I was just beginning to build rapport with

the staff on the ICUN, one of the nurses approached me asking for help. Eyes rolling,

she explained that the evening before, the mother of an adult patient had reported

this nurse to Patient Services with a grievance about her daughter's care. Mrs. A had

reported the nurse for administering insulin to the patient, her daughter with

diabetes, when her blood sugar level indicated a need for it per hospital protocol.

This conflict resolved but certainly set the stage for continued conflict between the

staff and this family.

When I entered the room, I knew only what I had learned from the medical

records and from the staff. This patient ("Anna") was 30 years old, had Type I

diabetes, hypertension, end-stage renal disease with dialysis, and had been admitted

to the ICUN due to her second hemorrhagic stroke. Although at this point she had

only been on the unit for 24 hours, the staff had already experienced her mother as a woman overly involved in and sometimes impeding her daughter's care. Staff also shared some statements that were critical of her appearance. I did not know what to expect, but hoped that I could ease Mrs. A's fears about her daughter's care and convince her to allow the staff to perform medical treatments per their protocol.

Upon meeting Mrs. A, I had to acknowledge that this woman had lived a difficult life. Although hospital stays do not lend themselves to best appearances, it was apparent that Mrs. A lived with few resources. She was a White woman in early middle age, with long unkempt hair and a wandering eye. She was quite short in stature and relatively trim for her age, and wore revealing clothing. However, she was quite anxious and defensive regarding Anna's health, making numerous statements indicating that she was very detailed in monitoring Anna's various conditions. Her immediate concerns in our first visit were minor, including desiring outcomes of laboratory results and evaluations from speech and physical therapy. However, she explained a long history of challenges in the health care system, including the following vignettes:

- Mrs. A shared that when her daughter was four years old, she read a gum wrapper listing the signs and symptoms of Type I diabetes, and realized that Anna commonly experienced each of these. Mrs. A immediately took her to the physician hoping that Anna could be tested for diabetes, but the physician dismissed her concern. Mrs. A continued to advocate for her daughter over the course of two years.

A physician finally tested Anna and discovered when she was six years old that she did indeed have Type I diabetes.

- Mrs. A, with some self-awareness of her appearance, spent a good deal of time attempting to convince me that she bought, cooked, and served the best food possible for her daughter. Although on limited income, she wanted me to understand that she was doing the best she could, buying fruits and vegetables as much as possible, and watching Anna's diet to keep an adequate balance of proteins, fats, and sugars.

- Mrs. A explained in great detail her experiences of oppression during hemodialysis treatments at the clinic. Because she performed her daughter's care at home and was familiar with her functional patterns, she did not understand why the clinic would not listen to her concerns during treatments. Both of Anna's strokes occurred during hemodialysis treatments, and Mrs. A believed they could have been prevented if the clinic had followed her advice. She was upset that Anna could not eat during treatment and expressed concern that Anna was not given appropriate levels of blood pressure medication before or during treatment.

In our current setting, with the backdrop of struggle and antagonism with medical providers, I recognized this mother as a strong advocate for her daughter. I acknowledged this recognition, and it was immediately apparent that Mrs. A felt heard. She expressed gratitude for my presence and in subsequent visits tearfully expressed her significant worries about Anna's ability to recover and regain health.

At the same time, I was unsure that my presence was entirely helpful over time. I seemed unable to help Mrs. A move beyond her struggle to a place of acceptance that the current medical treatments were beneficial for Anna. Instead, she continued to perseverate on her historical struggles with the medical system and continued to interfere with the medical care provided by staff. Eventually, the staff brought in a diabetes educator in hopes of offering education about diabetes protocols, healthy behaviors, and goals of care, but Mrs. A refused.

Questions now began to arise regarding Mrs. A's mental health. Out of concern for Anna's health under her mother's care, the staff began to wonder if this patient suffered from what they referred to as "Munchausen syndrome by proxy," implying that Mrs. A was creating Anna's poor health outcomes.

These murmured suppositions were little more than rumor for a week or two. However, a questionable event occurred. The providers determined that Anna was medically ready to move to the floor unit from critical care, but Mrs. A objected and did not believe her daughter was ready for less intensive care. On the same afternoon that she moved to her new room, Anna experienced a serious medical event involving unconsciousness and was immediately moved back to critical care. Upon this unusual event, fervent rumors flew among staff; they believed Mrs. A had medicated her daughter and caused this event in order to move her back to the unit. From then on, Anna was treated with caution and was assigned an in-room sitter to ensure her safety.

As this antagonistic relationship developed, one of the physicians with extremely proficient communication skills ("Dr. B") arrived on service. I joined Dr. B

in Anna's room to see if she could foster a relationship and inspire Mrs. A to understand the hospital's goals for her daughter's health. I was duly impressed with Dr. B's ability to create rapport with Mrs. A as she expressed understanding of her protectiveness of Anna as a good mother. However, two events created distrust. First, Dr. B shared the same concern as the staff about Anna's safety and Mrs. A's mental health. To that end, she requested a psychiatric consult to determine Anna's decision-making capacity with a secondary goal of assessing Mrs. A. In this assessment, it was determined that Anna did not have capacity for complex decisions, but did have adequate capacity to choose her mother as healthcare agent. In his unofficial observations of Mrs. A, the psychiatrist noted that she appeared able to make reasonable choices for Anna's care. Although Mrs. A remained in place as health care agent, she felt judged by the presence of the psychiatrist and worried that efforts were in place to remove Anna from her care. Her concern caused increased distrust in the medical team and fractured her relationship with Dr. B. Second, in her meeting with Mrs. A after the psychiatric consult, Dr. B, like many others, attempted to convince Mrs. A to accept the conditions set by the hospital for her daughter's care. Mrs. A was objecting to these conditions every time a medical intervention was attempted. Dr. B used the extremely logical explanation that every health intervention we undertake has potential benefits and risks of harm, and that the potential benefits of accepting treatment significantly outweighed the high risks of refusing treatment offered by the hospital. At this point, Mrs. A turned away from the physician and remained steadfast in her objections.

After this meeting, I felt that we were approaching a dangerous climax for this family with a potential to seriously damage their trust in the healthcare system. I spent some time reflecting on Mrs. A's experience and remembered my first impression of Mrs. A as a fighter. Upon consideration that every provider in the ICUN thus far had attempted to convince her of their positive intent and beneficial treatments, I wondered if anyone, including myself, had made the simple move to ask Mrs. A about her experience and her reasons for making decisions in which she refused recommended treatments.

The next day, I entered Anna's room with no agenda except to rebuild trust and listen to Mrs. A's reasoning. She tearfully expressed understanding of her current antagonistic relationship with staff and providers and communicated high levels of stress due to this situation. She stated that her goal was to get Anna home with a peritoneal dialysis catheter, which would allow them to avoid dialysis clinics altogether because they would perform dialysis treatments at home. In order to get to that point, however, much of the conflict in the ICUN needed resolution. So I asked her what she wanted and why, and wrote down each of her desires with the intent of helping her communicate with the physician on duty and with the caveat that I could not promise that he would agree. She requested the following:

1. Mrs. A wanted to be allowed to manage Anna's blood sugar and insulin administration. She explained that the staff was already allowing her to, but she wanted to have official authorization.

2. Mrs. A requested a change to Anna's blood pressure medication because the current regimen was not working well. Although it had

been changed recently to the current regimen, she observed that Anna's blood pressure was not stable.

3. The final, and most critical negotiation, concerned the use of heparin, a blood thinner, during dialysis. Mrs. A was refusing the use of heparin because she was concerned about Anna's vision. Per Mrs. A, Anna suffered from bleeding in her eyes and had been advised by her ophthalmologist to avoid heparin; he had told her that heparin caused a risk of further bleeding and vision loss for Anna. Mrs. A further explained that loss of vision for Anna would mean a significant loss of quality of life because each of the activities she enjoyed involved her vision, including video-related activities and reading. She clarified that she was choosing to refuse heparin in favor of retaining quality of life for Anna. We talked briefly about the risks of refusing heparin during dialysis, including a pulmonary embolism, which could cause another stroke or death. She was very familiar with this possibility and offered that in the past, providers in dialysis would "flush the line" with saline to help prevent blood clots. Finally, I asked her what she would do if any of these known risks occurred. She understood the question, and, looking down at the floor with the difficulty of her statement, she stated, "I would know I chose quality of life."

After our lengthy conversation, I called in the physician, who was currently performing rounds on the unit. I explained to him the conversation I had with Mrs. A and allowed her space to verbalize her healthcare choices. He appeared to remain

uncomfortable with this request and again explained the risks of refusing heparin to Mrs. A. In response, she expressed complete understanding, expressing her desire to protect Anna's quality of life. The physician consented to her refusal. After he left the room, she appeared to feel relief and gratitude that he and I had taken the time to listen and understand her wishes.

After this, Mrs. A and Anna moved to the Neurology floor unit safely, Anna had a procedure to place a peritoneal dialysis (PD) catheter, and they were eventually moved to the Renal floor unit to ensure that the new dialysis method worked well. I continued to follow them through their hospital stay, and observed that Anna improved greatly and Mrs. A became significantly calmer as her daughter's acute medical care needs reduced.

Analysis

This case brings up multiple themes that lead to conflict in the healthcare system, complicating the provision of medical services and the relationship between patients and their care providers. First, I consider the effect of Mrs. A's appearance, education, and level of demands she placed on the system as affecting the relationship. Next, I discuss the perception that she was non-compliant and possibly suffering from a mental illness, causing her daughter's medical condition. Finally, I reframe these ideas from a social work perspective and highlight the need for viewing difficult patients and advocates through a lens of oppression.

Consider the effect that Mrs. A's appearance probably had on her relationship with the medical team. Medical providers, along with humanity as a whole, are susceptible to the social mores that lead us to associate beauty with health and

other positive characteristics (Jutel & Buetow, 2007; Stafford, La Puma, & Schiedermayer, 1989). In appearance alone, Mrs. A, as an advocate for Anna, was vulnerable to judgment because she was not a paragon of beauty by societal standards. Because she had a poor appearance in both physical characteristics and dress, the response of her medical team was less than favorable. At very least, it left her open to judgment by nursing staff, who engaged in derogatory conversation about her appearance. From my standpoint, it seemed that her appearance and choice of attire led to an assumption that she had poor judgment and was making immoral and possibly illegal choices for her daughter's care.

However, it cannot be assumed that her appearance alone led to her fractured relationship with the medical team. We might also examine her educational status and personality when considering their mutual disregard. In a recent study, Street, Gordon, and Haidet (2007) found that physicians were more apt to engage in patient-centered communication with patients whom they perceived as "better communicators, more satisfied with care, and more likely to adhere to treatment" (p. 594). Furthermore, the research found that if patients were more positive and involved, physicians were likewise more involved with their communication practices (Street et al., 2007, pp. 594-5). While Mrs. A was extremely involved, it cannot be said that she was a good communicator, satisfied with her care, or feeling positive with regard to her daughter's care. Instead, she was fraught with worry, complaint, and, in her communications, perseverated on minute details and historical transgressions in her daughter's care. Notably, Street et al. (2007) found that when patients were perceived as "less effective communicators and less

satisfied" with their medical care, physicians treated them with disrespect and disagreement more frequently (p. 595). Because Mrs. A presented with an established level of concern and distrust of the medical system, it was very difficult for providers to convince her of their good intentions. This caused frustrations among the providers and a mutually antagonistic relationship, leading to breakdowns in communication.

This breakdown was further exacerbated by her level of demand on the existing system. Studies have shown that more demanding and hostile patients have difficulty establishing a therapeutic relationship with providers, are less trustful of providers, and may be less adherent to recommended treatments (Burns, et al., 1999; Christensen, Wiebe, & Lawton, 1997). In the case at present, Mrs. A could be labeled similarly as a difficult patient surrogate decision-maker; she intervened at every level of Anna's medical care, she was steadfast in her belief about Anna's healthy blood sugar levels and refused further diabetes education, and she exuded distrust of the medical system. One member of the team noted that Mrs. A was making it harder for Anna to get better because she was not letting them do their job.

As this difficult relationship progressed, the team began to reorient their view of Mrs. A. Rather than simply distrustful and difficult, they started to consider her non-compliant. Although the right to refuse treatment is generally acceptable in the course of medical care, in this context, Mrs. A's refusal of treatment was unusual. Mrs. A wanted to continue treatment, but requested to eliminate specific elements of those treatments, such as following the hospital diabetes protocol; without that

protocol in place, the medical team believed Anna's health was placed at unjustified risk. Essentially, because the medical team believed that the treatments Mrs. A refused were both accessible and central to Anna's safety and health, they began to consider Mrs. A noncompliant. One definition is provided by Kleinsinger (2003):

> 1) the patient's medical problem is potentially serious and poses a clinically significant risk to length or quality of life; 2) at least one treatment exists that if followed correctly, will markedly reduce this risk; 3) the patient has easy access to the treatment or treatments; and 4) the patient deviates significantly from most patients (with similar medical problems) in degree of compliance with medical advice, treatment, or follow-up in a way that directly or potentially jeopardizes the patient's health or quality of life (p. 18).

Beyond the health risks to the patient, I observed additional side effects of noncompliance in this case. First, Mrs. A's refusal to accede to diabetes protocols exacerbated an already distrustful relationship. Through rejection of recommended treatments, Mrs. A demonstrated that she did not trust the hospital protocol to serve Anna's needs, and thus did not trust the providers. As she exhibited less trust in their recommendations, the providers began to dismiss her. Second, as her noncompliance continued, the staff felt increasingly stressed. Providing direct care was contentious as she repeatedly refused insulin and attempts to intervene through diabetes education. Because noncompliance with diabetes recommendations can lead to significant health risks, the staff grew more concerned about Anna's well-being. In particular, she seemed vulnerable to the outcomes of uninformed and risky decisions that her mother made as her surrogate decision-maker. Considering that this young patient had a significant medical history already, Mrs. A's history of medical decision-making became suspect.

Munchausen syndrome by proxy (now Factitious Disorder Imposed on Another) is considered a form of child abuse; a parent diagnosed with this syndrome fabricates an illness in his/her child, forcing that child to undergo unnecessary medical procedures and tests, usually arising from a parental desire to receive attention (Meadow, 1977, American Psychiatric Association, 2013). A related disorder, distinguished by Burton, et al. (2015) as "Munchausen syndrome by adult proxy" (MSAP), is given less attention, but is similar in definition; the primary difference is that the victim is a dependent adult (p. 32). In their study, Burton et al. (2015) noted that perpetrators of MSAP presented as overly involved and sometimes intrusive in hospital care. Given that these definitions require the fabrication of illness, and that Anna was actually quite ill, it was difficult to definitively apply a MSAP diagnosis to Mrs. A. However, given Mrs. A's very involved role at the hospital and in her daughter's care, along with her dismissal of hospital protocols and the strange event of unconsciousness after moving to the neurology floor, the staff was concerned about the possibility of abuse as a cause of Anna's continued poor health. It is possible that medical abuse existed, whether intentional or out of ignorance with regard to medical treatments, but the staff did not pursue intervention by the local authorities, so this remains uninvestigated.

This case is representative of ways in which health care is ill-equipped to recognize and respond to the complex social dynamics of its patient population. Given the number of challenges to the medical system that this family presented, I believe it worthwhile to consider the perspectives of patients and caregivers in

similar circumstances. In cases like these, it is essential to keep social dynamics in mind as we move toward a person-centered model of care.

First, let us consider the life circumstances of Mrs. A and her daughter Anna. During the course of my time with her and during our visits, it was clear that they lived on a fixed income. They relied on Medicaid for health insurance and received Social Security Income due to Anna's disabilities. Although Mrs. A made references to working in food service and healthcare settings, her employment experiences appeared sporadic prior to Anna's health decline. At the time of Anna's admission, Mrs. A worked as Anna's primary caregiver, a position that required most of her time and energy.

Within this context, many of the assumptions made by the medical team can be brought into question. The socioeconomic status of this family most certainly affected their appearance. It is well known that people living in poverty have fewer choices; resource constraints limit their options in basic necessities such as food or shelter. Considering these constraints, Mrs. A may not have had the resources to spend on her appearance. Furthermore, it is probable that, as a single mother with few resources, she felt increased stress in the hospital environment while seeking care for her daughter (McIntyre, Officer, & Robinson, 2003). Unfortunately, it is also possible that Anna's physicians more readily dismissed Mrs. A as an adequate caregiver due to her appearance. As Stafford et al. (1989) wrote, "physicians ought to become aware of their conceptions of beauty and perfection. Studying aesthetic values would help medical students recognize the role these socially conditioned conceptions of beauty play in their perception, treatment and diagnosis of the sick"

(p. 228). Physicians strive to promote health and well-being; while they are susceptible to the human reflex of first impressions, one hopes that a movement toward person-centered care would encourage the work of looking beyond initial appearances in providing care.

Similarly, Mrs. A's behavior was possibly a result of her long history with the medical system. From the beginning of her daughter's journey with diabetes, when she found it difficult to convince physicians to perform diagnostic tests, Mrs. A experienced a struggle in communication with the medical system. Additionally, she believed that other experiences with health providers led to Anna's incidence of strokes. Assuming these were accurate depictions of events, it is evident that Mrs. A arrived in the hospital with an underlying sense of distrust in the medical system. Much research has been done regarding distrust and medicine; an absence of trust in the patient-provider relationship can be based on a belief that the provider will not act in the patient's best interest (Hall, et al., 2001). Furthermore, an absence of trust in the medical system has been shown to lead to diminished treatment adherence and length of relationship, or continuity with the physician (Thom, et al., 1999). Given that trust is an essential element of the patient-physician relationship and of promotion of good health in the population, it seems that physicians should work toward improving the trust relationship when faced with a difficult patient or caregiver. Fiscella et al. (2004) found that physicians who employed methods of patient-centered care and explored the patient's experience of illness built a more trusting relationship with patients. Dismissal of a difficult patient or caregiver is not therapeutic for that patient's well-being.

It is also possible that poverty and generalized distrust of the medical system affected the most egregious element presented by this family: the significantly poor health of a relatively young patient. Anna presented with renal failure, high blood pressure, and retinopathy, all conditions known to be complications of diabetes (Pambianco et al., 2006). Notably, the rate at which these complications occur has been decreasing over time with improved methods for glycemic control, but studies have also shown that low socioeconomic status is an indicator for poor glycemic control and thus higher rates of complications (Pambianco et al., 2006; Secrest et al., 2011). Multiple recent studies have shown that food and other material insecurities are associated with poor glycemic control in patients with diabetes (Berkowitz et al., 2015; Mayer et al., 2016). Given that the cost of diabetes medications is prohibitive, even with health insurance in place, patients with low socioeconomic status struggle to maintain glucose control (Ngo-Metzner, et al., 2012).

A significant aspect of my conversations with Mrs. A was the amount of energy she spent in attempting to convince me that she tried to buy the healthiest food possible for Anna, shopping at discount food stores so that she could stretch her budget to buy yogurt, fruits, and vegetables. Her story is reminiscent of the essay by Feudtner (2005) on the beginnings of diabetes interventions and the definitions of success and failure in treatment of a chronic illness. Feudtner (2005) writes that "Arnold" was an early recipient of insulin and nevertheless died at the young age of 33 due to complications from diabetes, despite the controlled insulin and diet regimens recommended by his physicians. Feudtner (2005) writes that diabetes treatment requires a dedication to control, and if patients cannot adhere to

a strict regimen, they carry "the burden not simply of [their] failing health but also of the medical attitudes that construed complications as the result of poor patient compliance and control – 'medical advice neglected'" (pp. 54-55). Similar to Arnold, are Anna and Mrs. A to blame for the lack of control of Anna's diabetic complications? I argue that we must look deeper into the assumptions of medical control and the challenges of poverty before judging the intent or efforts of Mrs. A in her caregiving.

Likewise, there exist challenges of bringing forth an accusation of abuse, or MSAP, in these circumstances. While it is true that Anna suffered multiple medical complications from diabetes and that her mother would probably benefit from additional diabetes education, it would require significantly more evidence to show that her mother caused Anna's complications with a malicious or self-serving intent. A parallel analogy might be the challenges of proving medical child abuse in the case of a child with complex medical conditions. These medical conditions are chronic in nature and cause significant developmental and functional limitations, creating a situation where the child's health is dependent on regular visits to various specialists (Petska, et al., 2017). Petska et al. (2017) note that numerous stressors affecting parents of children with chronic illness, such as fatigue, concern, requests for further examinations or second opinions, and health literacy barriers, can be misconstrued as indicators of abuse or Munchausen's syndrome by proxy. Thus, as parents of children with serious illness find navigating the health system more urgent and more difficult, their risk of being negatively labeled by the medical system also increases. Further, provider factors, including the delay of diagnoses

through lack of communication or provider bias, can create susceptibility to abuse accusations (Petska et al., 2017). The researchers recommend that abuse "not be viewed as a diagnosis of exclusion but rather considered concurrently with other possible medical explanations for the illness," and that a longitudinal and person-centered inquiry be implemented to be sure of the abuse prior to accusation (Petska et al., 2017, p. 259). Similarly, although a number of Mrs. A's behaviors are similar to those that typify abuse, they could just as easily be symptoms of an overstressed, concerned mother without adequate health literacy or understanding of her daughter's disease process. In this case, rather than a quick condemnation, a better strategy might be to approach her with a goal of mutual understanding and respect.

Caring for the difficult patient is a common subject in the literature, with a common conclusion that it is not necessarily the patient who is difficult in isolation, but that the relationship is difficult (Forrest, 2012; Haas, et al., 2005; Miksanek, 2008). A solution, then, is to consider reframing our approach to difficult patients. Rather than allowing our assumptions and frustrations to rule our communication with patients, it would benefit all if we could employ communication with an intent to understand and respect the patient's experience of illness.

CHAPTER 4 – MRS. F

Narrative

I continued to assist patients through counseling and advocacy, but I was not always able to improve their hospital experience except through emotional support. Although I was in a unique position to relieve suffering of patients in the hospital through being present to provide support, the cause of discomfort sometimes remained undiscovered. The following case, involving a woman in the ICUN with an unknown condition, exemplifies a context in which I was witness to both the effect of uncertainties in healthcare and patient perception of bias. Unfortunately, there was not a satisfactory resolution to either problem; at the same time, the support I offered this patient helped to mitigate her distress during this admission.

As ICUN rounds concluded one morning, the attending physician pointed out a room to me, indicating that the patient within could use some support because she was the mother of three small children and was worried about being in the hospital. Her records indicated that she was admitted due to generalized severe pain in her legs that had not yet been diagnosed.

When I met Mrs. F, an educated and well-appointed African-American woman in her mid-thirties, she seemed sleepy but hopeful that her pain issues could be resolved. She indicated that she was concerned about her kids, ages 8, 7, and 4; her leg pain had interfered with her ability to be an attentive mother and she worried about being away from them in the hospital. She hoped that the doctors could figure out what was going on. She jokingly added that she did not want to end up on the 5th floor again, indicating the behavioral health unit of the hospital, and I

assured her that I was not visiting to make any mental health recommendations, but just wanted to make sure she was doing ok. She also shared that she took anti-depressant medications and that they were helpful. She further told me that her previous clinic suggested a diagnosis of fibromyalgia and that she had recently started taking medications for its treatment. She shared more about her family and friends who were helping with the kids while she was hospitalized, and it was apparent that she had a strong community of support. Her husband joined us, bringing Mrs. F food from a local restaurant, and I left, telling her to request me if she felt she needed additional support. She smiled and appreciated the visit.

The next day, a nurse approached and said that Mrs. F was asking for me. Upon entering her room, I noticed that Mrs. F looked very anxious. She shared that her treatment the previous afternoon had been terrible, and she just needed to tell someone because she did not feel like she could trust her nurse anymore. She related that the previous day the physician told her that she wanted to perform a spinal tap in order to attempt a diagnosis for her pain. Mrs. F shared that she was terrified of needles and was unsure of the procedure from the outset, but if it were the only way to diagnose her, that she would consider it. From that point forward, she admitted that she was quite anxious about the procedure and did not feel confident in her ability to hold still enough for the needle to penetrate her spinal cord safely. Mrs. F further shared that her nurse worked hard to calm her anxiety, and eventually convinced her to do it by telling her it was the same as an epidural. Here, Mrs. F laughed, saying that her experience was nothing like an epidural. She was taken down to the radiology suite, and when she saw the narrow table upon

which she would be placed and she learned more about the procedure, she began to shake. Her fears about the procedure increased and she decided she did not want to go through with it. Her nurse continued to attempt to convince her, however. Mrs. F related that she felt her nurse was berating her, even asking her at one point, "who is going to take care of your children if you can't get better?" She asked her nurse if there were any anti-anxiety medication options, and the nurse became short with her. Eventually she brought her a medication, but it did not take effect quickly. At this point, it sounded like Mrs. F was in a full-blown panic. Also, in the midst of this crisis, one of the radiology technicians approached her and quietly told her that she did not have to do the spinal tap if she did not want to; this gave her a modicum of solace. Eventually, the procedure was attempted, and they successfully administered a local anesthetic, but she could not lay still enough for the spinal puncture. She also shared a history of distrust of medical systems due to a past experience with a medical provider who was not truthful about the outcome of an intervention. Mrs. F felt very troubled, both because of her inability to go through with the spinal tap and because she held concern that her nurse disliked her; after the failed procedure her nurse brought her back to her room without comment, and kept her distance for the rest of her shift.

After she related this story, I sat with Mrs. F and provided counseling and support. She remained concerned that her nurse did not like her, and I acknowledged this anxiety but assured her that her nurse was a professional and would treat her well (the same nurse was assigned to her room on this day). I further offered her comfort that she had not done anything wrong and that she was

well within her rights to refuse treatment. She was grateful for the support and asked if I could come back when the physician visited.

In the meantime, I approached her nurse in hopes of better understanding what had happened. The nurse admitted that she had told Mrs. F that the spinal tap would be like an epidural and that she had reminded her that she needed to get well for the sake of her children, but that she was also frustrated. She did not understand why Mrs. F would come in with pain and refuse any diagnostic measures that needed to be taken. She then shared that Mrs. F had previously been on the "psych unit" and she thought this might be a mental health issue. She also shared a suspicion that Mrs. F might be a drug user because the amount of anti-anxiety medication she was administered in the radiology suite did not work. I did not know what to say to these statements due to my relative lack of experience with these matters. I did let her know that Mrs. F was feeling concerned that she had hurt their therapeutic relationship by choosing not to go through with the spinal puncture, and the nurse was surprised, saying that she very rarely had issues with her patients.

A little later in the afternoon, I joined the attending physician as he was discussing Mrs. F with another provider. He indicated a belief that she was faking her pain in order to get prescriptions for analgesics. He further shared that in addition to refusing the spinal puncture through her inability to complete it, she refused an electromyogram. Given that this diagnostic procedure entails placing two needles in a muscle and running an electric current between them, and that Mrs. F was afraid of needles, I did not find this surprising. After this conversation, we went into the room, where the physician examined Mrs. F and let her know that without

more diagnostic testing, he could not help her. He recommended that she return to the clinic that had diagnosed the fibromyalgia for further workup. After he left the room, I stayed behind to make sure she felt that her questions had been answered, and she indicated that she felt better about the situation and was doing ok.

When I checked back in with the physician, he confirmed his belief that she was lying about her pain. He shared that, because she could still walk around the room and that she could raise her heel up in a bedside examination, her pain was minimal and her functioning was adequate. I admitted a lack of knowledge about neurology, but did ask if there could be any other explanation. He simply looked at me and shook his head.

Later, I learned that she was discharged that same evening, but had returned to the emergency department two days later with the same leg pain. She was seen by the same attending neurologist and was again discharged without a diagnosis. I did not see her again.

Analysis

I found this case very distressing. There was a significant lack of information along with a significant lack of empathy for this patient. At the same time, she was placed in ICUN due to a lack of beds in the Neurological Intermediate Critical Care Unit, which serves patients of less acuity. There is a possibility that her treatment would have been different in a less acute context. Furthermore, I acknowledge that the providers and staff of the ICUN have much more depth of experience with their populations, giving them a different perspective of this patient's symptoms and behaviors. However, I do not believe this depth of experience should preclude the

38

importance of acknowledging each patient's individual experience with struggle and success in life.

First, this patient presented numerous questionable variables that made her care difficult. Her symptoms were generalized; she described being in so much pain that she found walking difficult, to a point that she was bedbound on some days. This, of course, was very distressing and made functioning as a mother of three very difficult. At the same time, the medical providers were unable to discover the source of her pain. At examination, she exhibited wincing and groaning, but was able to move her legs and walk in the room on occasion. Furthermore, her refusal of diagnostic testing that could offer additional information about the source of her pain confounded the providers. That refusal both stymied their ability to treat her pain and increased suspicion that her pain was not significant enough for her to exert effort in order to find a diagnosis and treatment.

From the combination of her refusal of diagnostic tests and their resulting inability to treat her pain, I believe doubt about her story arose for the provider and nurse. Notably, during our conversation, the nurse asked me why Mrs. F even came to the hospital if she wasn't willing to try to fix her problem. Because this patient presented as outside the norm of patients treated in the ICUN, and because the staff and provider were so limited in information, I believe they had difficulty understanding how to solve her medical issue. In the end, the staff and provider used their existing knowledge to explain this experience, looking to Mrs. F's past medical history and their previous history with patients presenting odd symptoms; these sets of information unfortunately led them to doubt her claims of pain.

First, Mrs. F had a history of mental illness – she openly acknowledged her

stay in the hospital behavioral health unit and her use of anti-depressant

medications. Because her case was difficult to understand, it appears that the

medical staff looked to her previous medical history to explain her condition. It is

natural to do so. Where diagnosis is dependent upon patterns of cause and effect,

there is a natural tendency to look for historical patterns to explain current

circumstances. Unfortunately, there also exists a significant amount of stigma in

society with regard to psychiatric diagnoses, which affects the treatment of persons

with mental illness, even if that illness is controlled effectively with medications.

Notably, a study by Hahn et al. (1996) found that patients with psychiatric disorders

were significantly more likely to be considered difficult by their physicians. The

research further found that physicians "felt ill at ease with difficult patients, often

felt that they were being manipulated, and in half of the encounters had some

private hopes that their patient might not return" (Hahn et al., 1996, p. 6). In the

current case, Mrs. F's psychiatric history was cited as a reason to doubt the

authenticity of her pain narrative; this doubt surely affected the dismissal of her

claims and her subsequent discharge without diagnosis.

Additionally, Mrs. F's nurse made a comment expressing suspicion about a

possibility of drug seeking behavior as an explanation for Mrs. F's simultaneous

claims of pain and avoidance of diagnostic measures. Given a recent upsurge in the

population of people with opioid addiction, there has been a heightened awareness

about drug-seeking patients, or patients who feign pain in order to receive

prescriptions for opioid painkillers. In 2010, the Centers for Disease Control and

Prevention reported that the "estimated number of ED visits for nonmedical use of opioid analgesics increased 111% during 2004—2008" (para. 1). Alongside that awareness are also increased efforts to identify drug-seeking patients and prevent them from acquiring the analgesics they pursue, including drug screens and shared electronic medical records between community facilities to monitor the frequency of requests for opioids by a patient. In this case, I was unaware whether Mrs. F was given a drug screen; however, her records did not indicate a pattern of frequent visits to area facilities in search of opioid prescriptions. Still, because this case contained both idiosyncratic events and unanswered questions, the staff wondered if another external factor, such as drug addiction, was the reason Mrs. F sought medical treatment for her pain.

Given the limited information they had available about Mr's F's condition and about the circumstances of her life, I believe the providers and staff were unable to treat her as well as they could. With a person-centered perspective focused on understanding her context and goals of care, the outcome may have been different.

First, I'd like to consider Mrs. F's history of psychiatric diagnosis. Mrs. F mentioned her psychiatric history rather than hiding it, but her apparent anxiety may have caused her to share this, as a means of controlling the information. When I looked more closely at her medical record, it appeared that her admission to the behavioral health unit was timed after the birth of her second child; although I do not know her diagnosis, that timing raises the possibility that she suffered from post-partum depression, a condition suffered by many mothers. Even if her condition was a somewhat more "normalized" mental illness, speculation into the

possibilities of her psychiatric history and its influence on her current situation were problematically permeated with stigma. As previously stated, a significant stigma follows people diagnosed with mental illness. As conceptualized by Link and Phelan (2001), stigma contains elements of "labeling, stereotyping, separation, status loss, and discrimination;" when these social barriers appear, the individual is faced with exclusion from social, economic, and political resources in society (p. 367). Stigma related to psychiatric disorders creates additional barriers as it creates fear of further judgment or discrimination. For example, people with mental illness have been shown to lack access to medical care for numerous conditions and to avoid necessary mental health treatments – the fear of stigma is significant in shaping individual behavior and often leads to unhealthy outcomes (Corrigan, 2004; Druss et al., 2010). As they allowed stigma to shape their relationship with Mrs. F, it appears that the provider and staff became less trusting of her pain and less committed to the therapeutic relationship. Through this, it appeared that Mrs. F felt alienated and that her distrust of the medical team increased.

It is possible that this relationship would have progressed differently through use of a "recovery paradigm" view of Mrs. F and her past medical history. In this strengths-based paradigm, people with mental illness are approached with the idea that they are survivors, have recovered from illness, and are capable and valuable members of society (Farley-Toombs, 2012). In the clinical setting, the recovery paradigm hopes to reduce the stigma that prevents people from receiving medical treatment "due to fear of being labeled as a 'psych patient' and its association with hopelessness, dangerousness, and incompetence" (Farley-Toombs,

2012, p. 153). Farley-Toombs (2012) further recommends two strategies to promote the use of a recovery paradigm in clinical settings: the presence of a psychiatric liaison to provide education to staff and physicians with regard to individual patients with mental illness and the use of therapeutic measures to establish trust through "listening to understand and responding" (p. 154). I believe each of these measures, if established in this case, would have assisted communication and established a stronger therapeutic relationship.

I believe I would be remiss to avoid exploration of the role of implicit racism in the treatment and dismissal of Mrs. F. In particular, the suspicion that she may have been seeking drugs when complaining of pain seemed misplaced given the presence of no supportive evidence. Racial and ethnic disparities in healthcare delivery and outcomes are widely known, and it appears that pain relief and opioid prescriptions are no exception. Studies have found racial disparities in the delivery of opioid prescriptions for specific bone-injury related pain and non-definitive complaints such as back pain (Singhal, Tien, & Hsia, 2016; Todd et al., 2000). The studies concede that it remains unknown if the disparities are due to differences in expression of pain or differences in the way a physician judges the pain and the patient's intent. Another study, a survey of young adults who had engaged in drug-seeking behavior, found that Caucasian patients seeking drugs were much more successful in deceiving their physicians than persons of color (Sanders, et al., 2016). Each of these studies implies that medical providers are susceptible to implicit bias while judging patient intent. The narrative that African Americans are less

trustworthy with opioids follows patients into clinical settings, leaving a substantial portion of the population without comfort and relief from pain.

While stigma and implicit bias may have played a role in the care of Mrs. F, the most prevalent factor in her lack of treatment was the inability of the treatment team to diagnose her pain, due to her refusal of diagnostic tests beyond the bedside exam. The source of this refusal was apparent – Mrs. F experienced anxiety related to the use of needles. This aspect of the present case brought to mind the classic medical ethics case of Mr. D (Siegler, 1977). Mr. D presented to the hospital with pneumonia that did not respond well to antibiotics; when presented with routine but uncomfortable diagnostic tests, Mr. D refused, asking for treatment but no more diagnostic testing. He eventually died from his pneumonia. The differences between Mrs. F and Mr. D are significant: Mr. D's illness was much more acute at the outset and his decision life-threatening. At the same time, there remains a similarity; they both arrived at the hospital in hopes of treatment for their illness and when presented with uncomfortable diagnostic testing, they refused. In both cases, the medical providers presented reasons for the recommended exams, but did not spend time attempting to understand the patient perspective. Perhaps, as Katz (1984) reasoned in the case of Mr. D, both of these patients would be better served if the provider had intentionally sought to elucidate and understand their reasoning, thus creating a trusting relationship and better mutual communication. In my encounters with Mrs. F, I found her very willing to explain her reasoning and experiences; if the providers and staff were open to listening to her perspective and

discovering mutually satisfactory solutions, would this case have turned out

differently?

I readily admit a lack of knowledge regarding people who have neurological

disorders, the typical population served in the ICUN, and a lack of experience with

patients feigning illness in the ICUN; this knowledge and experience gives providers

and staff a particular and informed perspective with regard to patients who present

with puzzling symptoms. At the same time, this knowledge and experience may

color their future interactions with patients in similar conditions. I hope to hold

strong to impartiality as I attempt to approach each patient with an open and

unbiased attitude; when we become beholden to our previous experiences and form

assumptions about groups, we can too easily fall prey to prejudice. This prejudice is,

at its core, antithetical to the medical ideal of "do no harm."

Every patient in the hospital comes with a lifetime of experience that leads to

the way they perceive themselves and interact with the world. They also bring with

them idiosyncrasies that can lead to ambiguity and uncertainty in the clinical

encounter. Further, these encounters, such as the one with Mrs. F, are often fraught

with a lack of information, stymieing efforts to diagnose and treat the conditions

they present to clinicians. How the hospital system manages these situations is

critical to the success of the encounter. In dismissing the patient and his/her

symptom narrative, there is a likelihood of alienation, lack of effective treatment,

and compromised therapeutic relationship. If, instead, clinicians approach their

patients with a desire to listen and understand their symptoms as a part of their

human existence, it is likely that the therapeutic relationship will remain intact even

if a diagnosis is not reached. In the case of Mrs. F, I was able to relieve her anxiety about her hospital encounter simply by being present to listen; although she did not receive a diagnosis, her confidence that the medical system was attempting to alleviate her suffering improved during our time together.

CHAPTER 5 - REFLECTIONS, CONCLUSIONS, AND RECOMMENDATIONS

The role of palliative care is to provide respite from the stressors of illness; whether the patient needs pain control, spiritual support, or emotional support, the palliative care model aims to relieve the "total pain" experienced by patients (Saunders, 1996, p. 1600). While the specialty of palliative care is primarily intended for patients nearing the end of life, there exists a place for palliative care in medical encounters earlier in the healthcare continuum; based in comfort and ensuring understanding between patients and providers, this palliative realm may be primary, but is still critical. I believe the CDSL role effectively served as a means for delivering this form of palliative care for patients during inpatient stays through implementation of supportive care. The care I provided entailed acknowledging the patient experience, empowering the patient as an individual of worth, and improving communication between patients, families, and providers; as a result of the combination of these activities, the CDSL became essentially a role for embedded clinical ethics, hybridizing social work and bioethics.

Hospitalizations, without regard for the cause, have the potential to be significantly stressful events. The hospital system and its actors work hard to create physiologic wellness in a context that presents challenges for both providers and patients. The providers are challenged by often conflicting demands of professionalism and efficiency in practice. The patients are challenged by the need to make serious and often expedited medical decisions while displaced from the comforts of home and while immersed in a foreign medical language and culture. The scene can be fraught with a lack of communication and conflicting ideologies,

creating tensions that may lead to an impasse, a degeneration of therapeutic

relationship, or harm to the patient. Although the pilot was short and my

experiences anecdotal, the role of CDSL appeared to hold a unique position from

which to serve the needs of each stakeholder in difficult situations. As I reflect on

this practicum, I am struck by the dynamic nature of the role, the significant

confluence of social work and bioethics in performing this role, and the overarching

benefits this role can have for the medical system as a whole. The CDSL role has the

potential to palliate a significant amount of existential suffering that occurs in the

hospital setting, by opening another line of communication and working toward

understanding among stakeholders in healthcare.

Versatility of the Role

One aspect of the versatility in this role was its usefulness across a broad

variety of concerns. As illustrated in the narratives in the previous chapters, I

encountered an extremely heterogeneous population of patients during my

practicum, including patients with terminal illness, chronic illness, and brief acute

episodes requiring hospital admission. Each patient was faced with a unique set of

circumstances and had a unique set of needs. The variety of circumstances

encountered required both a broad understanding of the consequences of illness for

a patient and family system and an adaptability to the different effects created by

specific types of illness. This role allowed me the flexibility to gather important

information in individual situations and proceed with education, advocacy, and

support for patients and providers alike.

Another illustration of this versatility was the position of the role in the hospital system. As an independent liaison, I found myself primarily supporting patients, but often providing support to providers and staff as well. This support took a number of forms, including brief informal counseling of staff and providers, documentation of my encounters with patients, and simply being present to ameliorate difficult situations with patients. Working in a hospital environment brings its own set of stressors. The physical and emotional burden felt by nurses and providers can lead to burnout and compassion fatigue, conditions that affect job satisfaction and the ability to serve patients well (Aiken et al., 2002; Kash et al., 2000). In this role, I was able to offer brief counseling to staff, primarily to validate feelings of stress and support the importance of self-care. A second important support for providers and staff was the documentation of my interactions with patients. Because I had the luxury of time to connect with patients, I frequently received more background information from the patient and family; this background information often illuminated a previously puzzling situation. By uncovering this information and subsequently sharing it with the treatment team via documentation, this role supported both the patient and the medical team by improving communication and opportunities for empathy. The presence of this role further served to support the medical team – during a number of exit interviews, several nurses cited a sense of comfort knowing that a role like this one could meet patient needs that they could not due to a lack of time and skills. Staff recognized the importance of obtaining a deeper understanding of the patient perspective, and were encouraged by the presence of the CDSL role to fill that need.

Finally, we must consider the variety of roles that acting as a CDSL required. These roles included counselor, educator, translator, and mediator of conflict. As indicated previously, I provided significant support to both patients and medical staff; in the stressful context of the hospital, there is ample opportunity to provide support. As counselor, I attended to the emotional needs of patients and staff as they waded through the sometimes difficult terrain of medical communications. As educator, I primarily served the needs of patients, providing information about the resources and limitations of what the hospital could offer. I connected them to resources such as comfort care or additional time with the provider to ask outstanding questions, and explained the limitations of the hospital by clarifying the procedures and concerns that providers might express. Similarly, I acted as translator for patients and medical staff; there were occasions when the miscommunication was due to lack of understanding the meaning of the other. On these occasions, the medical staff and patient were both speaking the same language, but the context and culture of each party in the conversation were foreign enough to the other party that the interaction resulted in confusion and misunderstanding. In this role I had the ability to take the time to understand the meaning behind the confusion and in effect translate this meaning, adding clarity to these interactions.

Finally, I acted as mediator of conflict more often than I expected. Although medical systems such as NH are implementing programs to improve physician communication, there often remains a communication gap in practice. The reason for this probably varies. Patients may not feel confident in the hospital setting to ask

questions; they may not have the medical literacy to know what to ask; there may

exist a language or cultural barrier to communication; or the physician may lack the

skills, time, or desire to engage with patients to more fully understand their goals

and desires for treatment. Without regard for the reason, this gap can lead to a

fracture and possibly conflict in the patient-physician relationship. As demonstrated

in a number of the narratives in the previous chapters, my role became one of

mediating these conflicts. As CDSL, I worked to understand the hopes, fears, and

experience of these patients while also educating them about their responsibilities

and options while in the inpatient setting. At the same time, I worked to provide this

information to providers and staff, offering education about the patient perspective

and opportunities to understand patient motivations and empathize with patient

experiences.

The Effect of Social Work and Bioethics Together

When colleagues would ask about my course of study, I would occasionally

receive an interesting response. The fact that I am studying both bioethics and social

work would give some people pause, presumably because the social work discipline

is not commonly combined with bioethics in our geographical area. I did not take

this response as a judgment of inappropriateness in the combination, but simply the

listener encountering a new idea or way of thinking about the use of bioethics in

practice. I believe these two disciplines work quite harmoniously together, and this

harmony was evident during my work as CDSL. Considering the variety of tasks I

faced while working as CDSL, the combination of social work and bioethics appears

perfectly suited to this role. In order to assess the situation, it was essential to

consider the effect of illness on a patient and family. I looked to the historical

functioning of the family, their understanding of the origins and treatments of

illness, and their understanding of the role of medicine – a foundational element of

social work. At the same time, this role requires a larger and more comprehensive

systems view of the health care system that is provided by bioethics; in order to

provide education to patients, families, and medical teams about their rights and

duties, effectively analyze situations as a neutral party, and mediate conflict of

interests in the hospital, an understanding of bioethics is essential. Together, social

work and bioethics offer a unique symbiosis that promotes balancing and

understanding of numerous factors and offers opportunities in resolving non-

medical needs in the hospital. It is worth examining the separate advantages and

perspectives of each discipline in more detail as well.

Social Work

During my role as CDSL, I accessed social work skills while supporting

patients who reached and articulated difficult decisions, caregivers who advocated

for their family members, and patients who were simply in need of additional

support while they endured the discomfort of the medical setting. Social work views

the human experience as one influenced by multilevel systems including biological,

social, and environmental factors. Throughout our lives, these systems have shaped

our perceptions of the world and our behavior. The acute care setting of the hospital

creates additional stressors that challenge the functioning and coping mechanisms

of patients and families. In this context, patients and families are required not only

to process the experience of acute illness, but also to make decisions critical to their

fundamental health and well-being. In order to understand the multiple stressors on patients and families as well as their understanding of themselves in the illness paradigm, I frequently found myself referring back to the social systems framework and typology of illness set forth by Rolland (1994).

In this framework, Rolland (1994) recommends that clinicians consider the practical, affective, developmental, paradigmatic, and historical effects of illness on an individual and family system. As an example, we might consider a patient newly diagnosed with a catastrophic illness, such as metastatic cancer. The patient and the family are certainly affected by the practical demands of the illness – the ensuing treatment demands will create significant stressors to familial cohesion, adaptability, and communication. The affective demands of the illness include the emotional stressors experienced by the patient and family, including grief for the loss of their previous security in health as they now face uncertainty. The developmental consideration requires that we look at the developmental stage of the patient and family. As people progress through the stages of life, they experience changes in numerous aspects of life including position in family and society, understanding of self and the world, and expectations for the future; a diagnosis of serious illness will be received and processed differently by individuals at different developmental stages of life. The illness also creates a significant and stressful impact as it interacts with the paradigmatic self-understanding of the patient and family. The patient and family may have to fundamentally redefine themselves as the illness causes physiological differences in abilities. Prior to the illness, they may have understood themselves to be "healthy," now they are "sick;" where they were

"strong," they may now become "weak." These paradigmatic shifts can cause serious existential struggles for patients and families as they experience the varying effects of illness.

Finally, Rolland (1994) recommends exploring the historical meaning of illness for a patient and family. They may process this illness in terms of past health crises, and may use this illness as they project ideas about the future and their understanding of mortality. Also entwined with these effects are the personal views of the specific illness as well as the generalized health beliefs of the individual and family. While I was working in this role, my expertise in social work served as a near-constant reminder of the competing variables in the lives of patients – their struggle in the hospital cannot be viewed in isolation from their experience of human existence.

Bioethics

With the perspective of clinical ethics in mind, I was able to draw back from the social work counselor role and consider the competing values of stakeholders in each situation. There is rarely a single right answer to conflict in the medical setting; while a single choice may appear objectively correct, additional information from varying parties will almost certainly illuminate new ways to conceptualize multiple good outcomes. As CDSL, in a mediator role, I actively sought the perspective of each party in order to reach a more complete understanding of situations, and also relied on ethical principles and theories to assist in evaluating acceptable courses of action. Given that my social work background requires me to advance the importance of individual self-determination of powerless individuals, and given that

there exists a power imbalance between physicians and patients, I found myself in a patient advocacy role frequently as I promoted the principles of respect for autonomy, non-maleficence, and beneficence (Beauchamp & Childress, 2009). Respect for autonomy, or the requirement that people be allowed to make decisions without interference from other parties, was broadly present in my support of patients. In most cases, providers and staff used the role of CDSL to help reveal patient goals; in doing so, the whole team was raising the importance of patient autonomy as they sought to provide care that aligned with patient values. In effect, through seeking improved decision-making, the CDSL improved respect for personhood and autonomy. In relaying these goals back to the medical system, this role allowed me to also promote the principles of non-maleficence and beneficence - as the medical teams desired both to avoid providing care antithetical to patient and family values and to provide care that would benefit the patient and family, they sought to follow these principles. The CDSL role simply allowed the medical providers access to additional and vital patient information that could help guide their care. The principle of justice was not frequently directly acknowledged in my daily interactions with patients, families, and staff, but it certainly was a consideration in my work. As I attempted to address misconceptions based in issues of discrimination, I encountered and attempted to resolve issues of social justice. Furthermore, the concept of distributive justice is an underlying theme in much of medical care; the distribution of resources is a consideration in the direct relationship between patients and the medical team as well as the systemic constraints felt primarily by the medical team. There were times that I offered

education to patients in order to help them understand the care the hospital and its staff could provide, allowing patients the opportunity to understand the systemic constraints and providing patients the opportunity to empathize with staff in their interactions.

I do not believe that the ethical context of this role can be limited to principlism, however. There are numerous other ethical theories that influenced my evaluations of situations encountered during this role, including the ethics of care, feminist ethics, narrative ethics, and virtue ethics; a brief overview of each of these theories follows.

The ethics of care requires that we evaluate ethical situations with an eye to relationships – witnessing and emphasizing the importance of care-givers and care recipients as we seek to care for those who are "dependent and vulnerable" (Sanders-Staudt, 2016). Perhaps obviously, as we support patients with serious illness and their families, we can identify them as recipients and providers of care within a familial system. Furthermore, we might consider that entire family system to be a recipient of care from the medical team. In light of this system of care, it is only appropriate that we consider the role of relationships and interdependence as we evaluate the situation.

Also important, feminist ethics focuses on the role of oppression, especially as it relates to the experience of women, and seeks to utilize ethics to eliminate existing oppressive systems (Gotlib, 2016). Similar to care ethics, I believe my role as CDSL must consider the systems of oppression of women in the hospital setting.

As frequent caregivers, both in families and as medical staff, the role of women in the hospital setting is crucial to uphold.

Narrative ethics looks to individual stories to help define human experience and both personal and general moral codes (Gotlib, 2016). As CDSL, I had the unique opportunity and honor to gather patient narratives and to communicate these narratives to the medical team. Each narrative brought with it unique sets of experiences, hopes, fears, and values; through listening to these narratives and then exposing them to the medical team, I believe a unique charactieristic of this role was the opportunity to expand the potential for empathy in the medical team.

Finally, virtue ethics in this context requires that each medical provider consider what a person of virtue would do prior to taking a course of action, and then follow that lead in order to strive for virtuosity (Athanassoulis, 2016). In light of the afore-mentioned ethical theories, it appears that a virtuous doctor is one who is willing to hear and respect patient and family values, and take the time to educate the patient and family about options for medical care. Given the reality of constraints experienced by the typical physician in the acute care setting, the role of CDSL created an opportunity for physicians to access patient and family values and provide options to patients in line with those values, in effect creating a conduit for virtuous action.

In her book, <u>The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures</u>, Anne Fadiman (1998) notes that while researching the experience of illness in a Western medical context by a Hmong family, her role was one of observation between involved parties. In this

role, she was on the edge between two perspectives, able to observe with neutral clarity the understandings of each party and the idiosyncrasies of the relationship. I believe the CDSL holds a similar position; I was able to hold a neutral stance while supporting both the medical team and the patients during moments of misunderstanding. In most encounters, I was able to assist in resolving conflict through aiding communication and translating positions to each party. In combination, social work and bioethics converge on a similar goal – to work toward understanding between patients and physicians in order to promote a therapeutic relationship and thus a better outcome for all parties involved.

Practicum Outcome - Measures & Potential

In a lecture on October 11, 2016, Bruce Jennings noted a particularly compelling observation in the evolution of medicine: when medical practice was more paternalistic in nature, physicians directed the treatment options; now, with a greater emphasis on patient choices, the physician might offer a list of treatment options to patients with a directive to make a choice, giving little guidance about the decision. In this role, I effectively offered guidance for patient decisions as I established patient trust, supported their identification of personal goals, and helped them understand and weigh treatment options.

As referenced earlier, the measures of success of the pilot were limited quantitatively, but I believe we were able to assess valuable qualitative measures for success. Additionally, I believe that these qualitative measures are significant enough to imply far-reaching and valuable improvements to the medical system.

Although subjective and anecdotal, one of the most prominent measures of success in this role for me was the gratitude expressed by the patients, families and staff I served. Many of my encounters with patients arose in situations fraught with intense emotions; while struggling with the burdens of living with serious illness, patients and families appeared stressed both by the requirements of the hospital and by conflict among family members and sometimes providers. My presence afforded patients and families the opportunity to process their choices in a safe way and to feel empowered as they moved forward with health care decisions. Patients appreciated this supportive presence, and expressed gratitude and satisfaction upon simply "being heard" by a representative of the hospital. Statements proffered by patients included countless expressions of "thank you," and sometimes queries regarding where they could write to offer gratitude to the hospital system for providing my presence.

Relatedly, I also received numerous expressions of gratitude and hopefulness from staff. When I began the practicum, I conducted a brief survey of nurses on the unit to inquire whether they thought this role would be useful, and received a resounding yes. Many nurses cited occasions in the past when they wished they had a reliable means of offering psychosocial support to families struggling with coping surrounding diagnoses or hospitalizations. When the pilot concluded, I conducted another survey, this time asking nurses if they still thought this role to be useful, and again received a resounding yes. A common sentiment was expressed concisely by a particular nurse; she stated that she found it comforting to know that I was available to provide support because she often witnessed the need for support but could not

provide it herself due to time constraints. A particularly eloquent physician noted that my presence was helpful; as he and his team focused on treating disease, my role was essential for treating the "dis-ease" experienced by patients.

The primary goals for this role remain steadfast in a desire for improved patient satisfaction and treatment; at the same time, these outcomes may also have implications for financial benefits to hospital systems. At a basic level, one can make a direct connection between patient expressions of gratitude to patient satisfaction with care received by the hospital system, which may lead to financial benefit to the hospital. First, given that the Patient Protection and Affordable Care Act of 2010 (U.S. Congress, 2010) denotes the patient experience of care as one of the five domains of quality care and offers incentives for hospitals to achieve measures of patient satisfaction, this role has the potential to be beneficial for NH through federal incentives. Second, increased patient satisfaction has significant potential as a marketing tool for any hospital system. As patients' satisfaction increases, they are more likely to recommend the care provided by the hospital, possibly creating further referrals to other patients and also creating a community-wide reputation for successful person-centered care.

Furthermore, I believe this role has the potential to reduce health care costs. As CDSL, I helped to effect earlier referrals to palliative care, reduced patient time on the critical care units, and reduced conflict between the care team and patients. Earlier identification of family goals aligned with palliative care and improved therapeutic relationships between providers and patients can produce benefits not only to the patient and family, but also to the hospital system.

A further possible long-term benefit of increasing satisfaction among patients and staff is the possibility of increasing retention of staff. Currently, there is a crisis in nursing; nurses feel overly stressed in their work, leading many to experience job dissatisfaction and burnout (McHugh, et al., 2011). While the work of the CDSL has little effect on the most stressful working conditions experienced by nurses, it has the potential to relieve some amount of stress in multiple ways. It may relieve nurses of stress related to addressing another aspect of patient suffering, it may make providing care to difficult patients easier as it alleviates patient stress, and it may reduce the stress felt by nurses as they also receive the benefits of direct support from the CDSL. While this is certainly a projected outcome, there is potential in this role to increase job satisfaction among staff, offering another fiscal benefit to hospital systems as its need to hire and train new staff is reduced.

Limitations & Recommendations

With these outcomes and potential benefits in mind, I believe the CDSL role is one that should be established in hospital settings targeting goals of person-centered health care. At the same time, I want to acknowledge some of the potential limitations of the CDSL.

There may be occasions in which the CDSL role has difficulty balancing the competing interests of patients and providers. As an example, in the case of Mrs. F, it is clear that the patient felt that her care was affected by bias; as a neutral party attempting to support her, I felt caught between two interests. In the interest of social justice, I could not ignore her perceived bias – it is widely known to be present in society and in healthcare. At the same time, in the interest of respect for

the clinical ability of providers and staff, and of preservation of my relationship with them in the interest of receiving future consults, I did not think it expedient to accuse them of bias without empirical data to support it. Although my lack of direct intervention with the providers might be a failing in the mission of social work, I believe this role can be effective in working against bias in other ways. First, my narrative in the patient's medical record indicating that she was uncomfortable with her treatment provides insight into her experience and hopefully increased self-awareness in the future actions of staff and providers. Second, in its neutral position, I believe this role can provide in-service education to staff across the hospital on the incidence and manifestation of bias in the hospital setting. With the ability to increase education, the CDSL can help affect the incidence of bias generally, if not acutely and specifically. I believe this process will work in most situations wherein the CDSL is caught balancing two seemingly oppositional values.

Some may also wonder whether the CDSL role will replace the need for staff and providers to practice empathy and problem-solving in their day-to-day interactions with patients. This concern indicates that rather than working to provide excellent care, staff might simply rely on the CDSL to "fix" situations with difficult patients. Without long-range empirical data, I cannot address this adequately, but I do not believe this will be an issue. In providing care, I believe that most staff and providers have the best interests of their patients in mind, and that they do what they are able to meet the needs of patients. At the same time, I believe that staff and providers are overburdened with patient loads and requirements of efficiency. Rather than supplanting the current efforts of staff and providers to

ameliorate non-medical patient needs, I believe the CDSL provides additional

coverage that staff and providers are unable to provide in the current systemic

model of hospital systems. It remains imperative that staff and providers receive

training in communication and empathy, but given the limited resources of time and

energy, the CDSL can provide supplementary care to help ameliorate situations that

are beyond the functional capacity of staff and providers.

      This role has remarkable potential for improving the patient experience, but

there remains a possibility for inconsistency between positive intent and actual

results upon implementation. The 1995 landmark study, the Study to Understand

Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT),

provides an example of when implementation of a program to improve

communication between patients and physicians had no effect on treatment

outcomes (Connors, et al.). In the program implemented by SUPPORT, a trained

nurse actively sought to understand the treatment preferences of patients with a

goal of communicating these preferences to the treatment team; however, the

results showed that patients in the intervention group had the same rate of death in

the intensive care unit, pain prior to death, and resuscitation when they had

indicated a preference to avoid it (Connors, et al., 1995). Without addressing the

specifics of why that intervention did not prove beneficial to patient outcomes, I

argue that much has changed since this study was performed throughout the

healthcare system. In the time since 1995, palliative care has emerged as a

respected discipline, bringing with it a culture that emphasizes the importance of

person-centered care. Also, we must consider that the development and broad use

of electronic medical records has made communication between various disciplines and different health care practitioners much easier. The ease of use of electronic medical records as a means of direct communication relies on the individual implementation by different hospital systems, but it is still creates increased accessibility to patient information and preferences. Nonetheless, even with these changes in health care that have created a more welcoming environment for improved communication, it will be prudent to proceed with vigilance that the goals of this intervention are being met, especially because the CDSL role presents difficulties as we attempt to define it concisely.

The CDSL role is unique. Although it requires skills and knowledge drawn from the fields of social sciences and from bioethics, its intent differs from the defined roles typically held by social workers or clinical ethicists in the healthcare context. My approach with patients, families, providers, and staff drew from clinical social work skills as I built rapport, sought to understand individual perspectives, and connected patients and families with internal resources such as palliative care. I drew from my knowledge of bioethics when I provided education to patients and families about the intent of the healthcare system in which they were immersed, education to providers and staff about patient rights and responsibilities, and mediation when necessary. I believe eliciting patient goals for care and the related hopes and fears about future health falls is influenced by both disciplines. The CDSL role is both nebulous, as it proves difficult to define, and essential, as it proves centrally important when it is truly needed for consultation.

As I attempt to define it more clearly, I consider the multiple roles I held in individual situations. I enacted the role of communicator, educator, mediator, counselor, and translator between patients, families and medical providers and staff. The CDSL role is both important and distinctive in the context of health care today. While nurses and providers can offer person-centered care within their professional capabilities, their extensive role-based duties limit their abilities to take on additional tasks, preventing them from eliciting the information required to provide truly person-centered health care. The CDSL role has the latitude to spend time supporting patients and gathering information in order to better understand their values and motivations as they pursue better health. Considering the overarching goals for patient-centered care that currently affect standards for healthcare delivery and the logistical conflicts presented by goals of efficiency and productivity, there exists a need for a role such as the CDSL; it can effectively improve communication and assist in aligning patient outcomes and values. In turn, as it provides supportive care to patients directly, the CDSL has a unique role in reducing patient stress in the hospital setting, thus reducing patient suffering and performing an essential palliative role.

The Future of the Clinical Decision Support Liaison

With the outcomes of this brief practicum in hand, the Patient Services team requested that six CDSL positions be implemented throughout the NH hospital system. I believe this position was crucial in providing comfort to the families I served and that it has potential for significant use as a means to prevent conflict and improve patient satisfaction across the health care continuum. As the health care

system seeks to improve person-centered care through improved communication,

roles like this one will prove essential to achieving this goal.

REFERENCES

Aiken, L. H., Clarke, S. P., Sloane, D. M., Sochalski, J., & Silber, J. H. (2002). Hospital
nurse staffing and patient mortality, nurse burnout, and job
dissatisfaction. *JAMA, 288*(16), 1987-1993.

American Medical Association (AMA). (2016). Principles of medical ethics. *AMA Code
of Medical Ethics.* Retrieved from https://www.ama-
assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-
1.pdf

American Psychiatric Association. (2013). *Diagnostic and statistical manual of
mental disorders* (5th ed.). Washington, DC: Author.

Athanassoulis, N. (2016). *Virtue ethics.* Retrieved from
http://www.iep.utm.edu/virtue/

Beauchamp, T.L. & Childress, J.F. (2009). *Principles of biomedical ethics* (6th Ed.).
New York: Oxford University Press.

Berkowitz, S. A., Meigs, J. B., DeWalt, D., Seligman, H. K., Barnard, L. S., Bright, O. M., . .
. Wexler, D. J. (2015). Material need insecurities, control of diabetes mellitus,
and use of health care resources: Results of the measuring economic
insecurity in diabetes study. *JAMA Internal Medicine, 175*(2), 257-265.

Berwick, D. M. (2009). What 'patient-centered' should mean: Confessions of an
extremist. *Health Affairs, 28*(4), w555-w565.

Burns, J. W., Higdon, L. J., Mullen, J. T., Lansky, D., & Wei, J. M. (1999). Relationships
among patient hostility, anger expression, depression, and the working

alliance in a work hardening program. *Annals of Behavioral Medicine, 21*(1), 77-82.

Burton, M. C., Warren, M. B., Lapid, M. I., & Bostwick, J. M. (2015). Munchausen syndrome by adult proxy: A review of the literature. *Journal of Hospital Medicine, 10*(1), 32-35.

Cassell, E. (2004). *The nature of suffering and the goals of medicine* (2nd ed.). New York: Oxford University Press.

Centers for Disease Control and Prevention. (2010). *Emergency department visits involving nonmedical use of selected prescription drugs --- United States, 2004—2008.* Retrieved from

https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5923a1.htm

Christensen, A. J., Wiebe, J. S., & Lawton, W. J. (1997). Cynical hostility, powerful others control expectancies, and patient adherence in hemodialysis. *Psychosomatic Medicine, 59*(3), 307-312.

Connors, A. F., Dawson, N. V., Desbiens, N. A., Fulkerson, W. J., Goldman, L., . . . SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA, 274*(20), 1591-1598.

Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist, 59*(7), 614-625.

Department of Health and Human Services. (2016). *Advance care planning.* Retrieved from https://www.cms.gov/Outreach-and-Education/Medicare-

Learning-Network-

MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf

Druss, B. G., von Esenwein, S. A., Compton, M. T., Rask, K. J., Zhao, L., & Parker, R. M.

(2010). A randomized trial of medical care management for community

mental health settings: The primary care access, referral, and evaluation

(PCARE) study. *American Journal of Psychiatry, 167*(2), 151-159.

Dunlay, S., & Strand, J. (2016). How to discuss goals of care with patients. *Trends in

Cardiovascular Medicine, 26*(1), 36-43.

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., . . . Department of

Business Administration. (2011). Person-centered care - ready for prime

time. *European Journal of Cardiovascular Nursing: Journal of the Working

Group on Cardiovascular Nursing of the European Society of Cardiology, 10*(4),

248.

Fadiman, A. (1998). *The spirit catches you and you fall down: A Hmong child, her

American doctors, and the collision of two cultures*. New York: Noonday Press.

Farley-Toombs, C. (2012). The stigma of a psychiatric diagnosis: Prevalence,

implications and nursing interventions in clinical care settings. *Critical Care

Nursing Clinics of North America, 24*(1), 149-156.

Feudtner, C. (2005). The want of control: Ideas and ideals in the management of

diabetes. In N.M.P. King, R.P. Strauss, L.R. Churchill, S.E. Estroff, G.E.

Henderson, J. Oberlander (Eds.), *The social medicine reader: Vol. 1. Patients,

doctors, and illness.* (2nd ed. pp. 41-59). Durham, N.C.: Duke University Press.

Fiscella, K., Meldrum, S., Franks, P., Shields, C. G., Duberstein, P., McDaniel, S. H., & Epstein, R. M. (2004). Patient trust: Is it related to patient-centered behavior of primary care physicians? *Medical Care, 42*(11), 1049-1055.

Forrest, C. (2012). Working with 'difficult' patients. *Primary Health Care, 22*(8), 20.

Gotlib, A. (2016). *Feminist ethics and narrative ethics.* Retrieved from http://www.iep.utm.edu/fem-e-n/

Haas, L. J., Leiser, J. P., Magill, M. K., & Sanyer, O. N. (2005). Management of the difficult patient. *American Family Physician, 72*(10), 2063-2068.

Hahn, S. R., Kroenke, K., Spitzer, R. L., Brody, D., Williams, J. B. W., Williams, J. B. W., . . . deGruy III, F. V. (1996). The difficult patient - prevalence, psychopathology, and functional impairment. *Journal of General Internal Medicine, 11*(1), 1-8.

Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in physicians and medical institutions: What is it, can it be measured, and does it matter? *The Milbank Quarterly, 79*(4), 613-639.

Hurwitz, W. (2005). The challenge of prescription drug misuse: A review and commentary. *Pain Medicine, 6*(2), 152-161.

Institute of Medicine, (2001). *Crossing the quality chasm: A new health system for the 21st century.* Retrieved from https://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf

Jagosh, J., Donald Boudreau, J., Steinert, Y., MacDonald, M. E., & Ingram, L. (2011). The importance of physician listening from the patients' perspective:

Enhancing diagnosis, healing, and the doctor-patient relationship. *Patient Education and Counseling, 85*(3), 369-374.

Jutel, A., & Buetow, S. (2007). A picture of health?: Unmasking the role of appearance in health. *Perspectives in Biology and Medicine, 50*(3), 421-434.

Kash, K. M., Holland, J. C., Breitbart, W., Berenson, S., Dougherty, J., Ouellette-Kobasa, S., & Lesko, L. (2000). Stress and burnout in oncology. *Oncology, 14*(11), 1621-1633.

Katz, J. (1984). *The silent world of doctor and patient.* New York: The Free Press.

Kleinsinger F. (2003). Understanding noncompliant behavior: Definitions and causes. *The Permanente Journal, 7*(4), 18–21.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*(1), 363-385.

Mayer, V., McDonough, K., Seligman, H., Mitra, N., & Long, J. (2016). Food insecurity, coping strategies and glucose control in low-income patients with diabetes. *Public Health Nutrition, 19*(6), 1103-1111.

McHugh, M. D., Kutney-Lee, A., Cimiotti, J. P., Sloane, D. M., & Aiken, L. H. (2011). Nurses' widespread job dissatisfaction, burnout, and frustration with health benefits signal problems for patient care. *Health Affairs, 30*(2), 202-210.

McIntyre, L., Officer, S., & Robinson, L. M. (2003). Feeling poor: The felt experience low-income lone mothers. *Affilia, 18*(3), 316-331.

Meadow, R. (1977). Munchausen syndrome by proxy. The hinterland of child abuse. *Lancet (London, England), 2*(8033), 343-345.

Miksanek, T. (2008). On caring for 'difficult' patients. *Health Affairs, 27*(5), 1422-
1428.

National Association of Social Workers. (2008). *Code of ethics*. Retrieved from
http://www.socialworkers.org/pubs/code/code.asp

Ngo-Metzger, Q., Sorkin, D. H., Billimek, J., Greenfield, S., & Kaplan, S. H. (2012). The
effects of financial pressures on adherence and glucose control among
Racial/Ethnically diverse patients with diabetes. *Journal of General Internal
Medicine, 27*(4), 432-437.

Otis-Green, S., Sidhu, R., Del Ferraro, C., & Ferrell, B. (2014). Integrating social work
into palliative care for lung cancer patients and families: A multidimensional
approach. *Journal of Psychosocial Oncology, 32*(4), 431-446.

Pambianco, G., Costacou, T., Ellis, D., Becker, D. J., Klein, R., & Orchard, T. J. (2006).
The 30-year natural history of type 1 diabetes complications: The Pittsburgh
epidemiology of diabetes complications study experience. *Diabetes, 55*(5),
1463-1469.

Pellegrino, E.D. & Thomasma, D.C. (1993). *The Virtues in Medical Practice.* NewYork:
Oxford University Press.

Petska, H. W., Gordon, J. B., Jablonski, D., & Sheets, L. K. (2017). The intersection of
medical child abuse and medical complexity. *Pediatric Clinics of North
America, 64*(1), 253-264.

Pollak, K. I., Alexander, S. C., Tulsky, J. A., Lyna, P., Coffman, C. J., Dolor, R. J., . . .
Østbye, T. (2011). Physician empathy and listening: Associations with patient

satisfaction and autonomy. *Journal of the American Board of Family Medicine, 24*(6), 665-672.

Rolland, J. S. (1994). *Families, illness, & disability: An integrative treatment model.* New York: Basic Books.

Sanders, A. N., Eassey, J. M., Stogner, J. M., & Miller, B. L. (2016). Deception and drug acquisition: Correlates of "Success" among drug-seeking patients. *Journal of Primary Care & Community Health, 7*(3), 175-179.

Sander-Staudt, M. (2016). *Care ethics.* Retrieved from http://www.iep.utm.edu/care-eth/

Saunders, Cicely. (1996). Into the valley of the shadow of death: A personal therapeutic journey. *BMJ, 313*(7072), 1599-1601.

Secrest, A. M., Costacou, T., Gutelius, B., Miller, R. G., Songer, T. J., & Orchard, T. J. (2011). Associations between socioeconomic status and major complications in type 1 diabetes: The pittsburgh epidemiology of diabetes complication (EDC) study. *Annals of Epidemiology, 21*(5), 374-381.

Siegler, M. (1977). Critical illness: The limits of autonomy. *The Hastings Center Report, 7*(5), 12-15.

Singhal, A., Tien, Y., & Hsia, R. (2016). Racial-ethnic disparities in opioid prescriptions at emergency department visits for conditions commonly associated with prescription drug abuse. *Plos One, 11*(8), e0159224.

Slort, W., Schweitzer, B. P. M., Blankenstein, A. H., Abarshi - Fatiregun, E. A. B., Riphagen, I., Echteld, M. A., . . . Deliens, L. (2011). Perceived barriers and

facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliative Medicine, 25*(6), 613-629.

Stafford, B. M., La Puma, J. L., & Schiedermayer, D. L. (1989). One face of beauty, one picture of health: The hidden aesthetic of medical practice. *Journal of Medicine and Philosophy, 14*(2), 213-230.

Starfield, B. (2011). Is patient-centered care the same as person-focused care? *The Permanente Journal, 15*(2), 63-69.

Stone, M. J. (2001). Goals of care at the end of life. *Proceedings (Baylor University. Medical Center), 14*(2), 134-137.

Street, R. L., Gordon, H., & Haidet, P. (2007). Physicians' communication and perceptions of patients: Is it how they look, how they talk, or is it just the doctor? *Social Science & Medicine, 65*(3), 586-598.

Thom, D.H., Ribisl. K.M., Stewart, A.L., & Luke, D.A. (1999). Further validation and reliability testing of the trust in physician scale. The Stanford trust study physicians. *Medical Care, 37*(5), 510-517.

Thoresen, L. (2003). A reflection on Cicely Saunders' views on a good death through the philosophy of Charles Taylor. *International Journal of Palliative Nursing, 9*(1), 19-23.

Todd, K. H., Deaton, C., D'Adamo, A. P., & Goe, L. (2000). Ethnicity and analgesic practice. *Annals of Emergency Medicine, 35*(1), 11-16.

U.S. Congress. *Patient Protection and Affordable Care Act*, H.R. 3590. Public Law 111-148. 111th Congress, March 23, 2010.

World Health Organization (WHO). (2014). *WHO definition of palliative care.*

Retrieved from http://www.who.int/cancer/palliative/definition/en/

You, J., Fowler, R., Heyland, D., Canadian Researchers End Life Netw, & Canadian

Researchers at the End of Life Network (CARENET). (2014). Just ask:

Discussing goals of care with patients in hospital with serious

illness. *Canadian Medical Association Journal, 186*(6), 425-432

CURRICULUM VITAE

EDUCATION

May 2017	Masters in Social Work, University of North Carolina at Chapel Hill
May 2017	Masters in Bioethics, Wake Forest University
May 2001	Paralegal Certificate, Meredith College
May 1997	Bachelor of Arts, Sociology, Grinnell College

ACADEMIC INTERNSHIPS

August 2016-April 2017	Masters in Social Work Field Placement, Acute Palliative Care Unit, Novant Health Forsyth Medical Center, Winston Salem, NC
June 2016-July 2016	Masters in Bioethics Practicum – Clinical Decision Support Liaison Pilot, Novant Health
August 2015-April 2016	Masters in Social Work Field Placement, Pediatric Enhanced Care Program, Wake Forest Baptist Medical Center, Winston Salem, NC

PRESENTATIONS

February, 2017	Julie and Mary – Questioning Competency and Intent. Clinical Ethics Network of North Carolina Conference (Case Presentation)